

ABILITY

CHINA'S DEAF
VIOLIN CRAFTSMAN

JOHN WILLIAMS
FIGHTING PARKINSONS

MOVIES
MOVIES
MOVIES

PEANUT BUTTER
FALCON

ZACK GOTTSAGAN &
SHELLEY GOTTSAGAN INTERVIEW

DARUMA

by KELLI MCNEIL

INTERVIEW WITH
ALEXANDER YELLEN

TWO WAYS HOME
A CHAT WITH

TANNA FREDERICK



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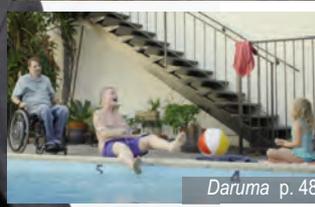




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It's summer time and my MX schools are rocking out! As I mentioned before, my classes have been on the East coast this summer instead of on the West. I'm excited to be over on the East, less driving for me and the weather has been beautiful!

My first class was in Illinois. I had already driven up there with my two Husky bikes and my trailer, so I knew I would be there in time. We had a few stops along the way to get some mountain bike riding in; it was

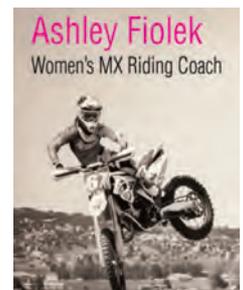


a nice slow trip. I had to pick my mom up from O'Hare airport so she could interpret for my class. I left the trailer at the track, and I used some of my free hotel points to grab her and hang out in Chicago for the day! We woke up nice and early on Saturday and headed to the track. It was a really beautiful track and a perfect day after Florida's never-ending heat. I had one of my biggest classes ever, and it was different because I had a lot of men/ boys in my class. It is normally only opened to women. It was a fun day, and a lot of the guys were friends. And, of course, they were all very competitive. So, whenever I showed them how to do something, they were trying to compete with each other :-). It made the class very fun. I also had a couple of cute little kids that were really into it and were trying their hardest to do everything I asked of them. As soon as the class finished, we left because we had a long drive to get to the next campground. My mom was not scheduled to fly out until Monday, so we had some time to set up at the campground and also to head back into Chicago to visit on Sunday. We explored downtown, had the most amazing sushi ever and took touristy pics at the famous Chicago "Bean"! So glad we had the chance to go to Joliet MX track and hold a class there.

The second class was being held up in Wisconsin on Labor Day weekend. My mom flew into Chicago again. We had packed up my bikes and trailer and were headed back to Chicago to pick her up. We realized we

couldn't really drive the truck and trailer into the airport area so my poor mom had to Lyft her way out to an empty parking lot! Thank God for moms! Right? When she arrived we had almost a four-hour drive to the next track. We made pretty good time and didn't arrive to the campground too late. We actually stayed at a campground that was connected to a casino/hotel! It was a beautiful spot and we were allowed to use all of the hotel's amenities. We had a great 2 day stay there. This time the class was for 2 days with 2 different groups of people. It was with a group called Off Road Youth Organization, the group teaches young riders the thrill and joy of riding! How great is that? They even provide the bikes! They mostly do trail riding with some of them doing a little MX. My class was a "reward" for all of their hard work throughout the year. The track was Sugar Maple MX and it was in the middle of corn fields and farmland, but so beautiful! The first day I worked with all the youth riders and members. We had a great time, and they were very eager to learn and to ride. We played some games, and at the end of the class my mom and I eat tacos with everyone and sat around a fire —It was a little cold.— I answered some questions and just hung out with everyone. It was a really beautiful day.

On the next day I worked with about 5 little kids and a couple of preteens. It was a lot of fun. We just worked on the kids track because a couple of the kids were on 50's, and there was no way they were getting on the big track! There was one little boy. He was only 5 but so cute, and he was very eager to learn. They all were! I had so much fun with them, but it was a long day for some of them. They were not used to riding like that! We played a couple of games at the end of the day and snapped some pics. I really appreciate them inviting me. After class, we had to hurry and start our long drive to Indiana for a night of camping. We were headed to Michigan next to visit some family and relax before I would be doing a Babes Ride Out class and camping experience with Husky and Fox! ■ ABILITY



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The Great Fall

Yes, I know it sounds exciting to spend some time in a wheelchair; the primo handicap spots, zipping downhill, boarding a plane first, getting moved to the front of the line at Disneyland, etc. Oh, the perks. Maybe it's been a dream of yours, but being a disabled person for over thirty years, it's not all fun and games.

Earlier this year, I somehow fell out of my chair. That's always a bit of a predicament, curled up on the floor wondering "now what?". When this happens—and it has too many times—I must call the fire department, and they send over a few husky fellows to scoop me off the floor and put me back in my chair. When they come in and see me lying on the floor, to avoid embarrassment, I begin kissing the rug and saying, "I don't know what it is about this carpet, but I just love it. I simply love it. Okay, that's enough of that. Can you guys help me into my chair?"

So, being in a wheelchair is not all fun and games. There's ups and downs. This year, one of those downs cost me a broken foot. I've been lucky throughout my wheelchair years to not have broken more bone on falls. The only time I did was when I once went skydiving. We discussed everything from jumping out of plane to opening the shoot. The only thing we didn't talk about was what the hell we were going to do for a landing. I'm still wondering how that part, the most important part, was overlooked. Anyway, as the ground rushed up towards me, I remember thinking, "Hey, we never talked about the landing, the most important part."

Somewhere in the tumble and roll and grunts my femur bones snapped. I chalked that up to "my bad." Since then, I really haven't had urge the fly through the friendly skies. Besides, I always look at the bright side, my chute opened.

Last Saturday, I was getting in my van and I had just made it to the top of the ramp then fate reared its ugly head. Suddenly, my hand slipped, and my chair flipped backwards. While in that falling state, I remember thinking to myself "This one is going to hurt." You know what? I was right, for a change. Anyway, luckily, I was able to think quick and use my head, my head to cushion my fall. Yes, my head hit the warm gentle hard cement driveway. Fortunately, my head is harder than the warm gentle hard cement driveway. I laid there dazed in the hot sun listening to the sweet sounds of the birds chirping, only to realize they were just imaginary ones circling my head, like the cartoons. As I laid there groaning two words kept popping up in my head, and I couldn't shake them no matter how much I tried. Those words were "now what?"

A little way away, my wheelchair sat peacefully in the driveway glistening in the sunlight. I wanted to whistle, slap my thigh and say, "Come here, boy. Come here. Go get help, boy. Tell 'em I'm trapped in a well." But I knew I didn't wheel around on Lassie. I had no choice but to go catch it myself. I wasn't planning on pulling myself back up on that thing. Oh no, I only know how to go down. I've yet to master going up.

Getting to the chair was going to be hard enough, but it was imperative, cause that's where my cell phone was. I just prayed I could remember the number for 9-1-1.

I felt like I was on the clock, not because I was gushing blood—That would come.—But it was close to 100 degrees out, and I was starting to feel like a shrimp on the barbie. Laying in the hot sun too long makes me anxious. Laying in the driveway in the hot sun too long makes me dead. I was hoping to flag a car rolling by on the street or catch a neighbor walking his dog, but, of course, not a soul was around. And, if by chance I did see a neighbor walking his dog, knowing my luck, he would probably run up to me and bite me or poop on me. Then who knows what the dog would do. My busy neighborhood had somehow turned into a ghost town. I was thinking the gardener might be around using the loud leaf blower, but then I remembered it wasn't seven in the morning and I wasn't sleeping.

I flipped and flopped doing my best to position myself for the crawl. It wouldn't be a long one, but I knew it wouldn't be a fun one. After many falls, I eventually made a habit of keeping my cell phone in the front pouch of my wheelchair. A crawl from bedroom to the kitchen could end up being an all-day event. But it's dealing with aftereffects that really suck. After a good crawl my elbows become raw and bloody then take a month to heal since I rip them back open every night in bed. This crawl would be on hard cement and not carpet. I just wanted to take a nap.

Anyway, I was able to make the crawl to the wheelchair although I was hoping some neighbor would hear the loud profanity blurts reverberating through the air and come outside and see what the ruckus was. No dice. Maybe I didn't swear loud enough or just didn't use the right words. Maybe they just figured I was drunk and couldn't get up the ramp or get my key in the door. Not the first time.

Luckily, my phone wasn't dead. A profanity laced tirade would've been heard, all the way to Boise, Idaho. When I called 911, for some reason it seemed more embarrassing telling them I was lying in the driveway then on the kitchen floor. When they got on the phone, I just had to say it, I couldn't help myself. "I've fallen and I can't get up." That's just comedy gold you can't leave on the back burner. It's not the first time I've fallen and had to call the firemen to come throw me back in my wheelchair. My only beef with them is... why do they have to put the sirens on? It's humiliating. It tells the neighborhood I'm clumsy. "Sounds like ol' Jerry Lewis fell out of his wheelchair again, Marge."

The fireman recognized me, and we chatted like old friends.

"Hey Bob," I greet the boys. "How's the wife and kids? Timmy still playing Little League?"

"Yup. Hit a dinger last week," Bob responds, positioning my wheelchair. "You hurt anywhere? Any cuts or bruises?"

"No, dodged another bullet," I reply.

"Ok, let's get you up off the ground."

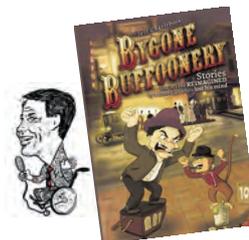
"Sounds good to me. Can we turn the siren off first? There's a crowd gathering around," I sheepishly ask.

Later that night my elbow swelled and hurt. I thought my arm was broken. Damn, I'm running out of limbs here. I couldn't get into bed that night. No arm strength so I stayed up the whole night and watched things on tv like a guy selling rare coins, a blender infomercial and Gilligan Island reruns. (Spoiler alert: Gilligan ruins their chance of getting off the island... in every episode.) Once football came on, I was good to go until I started losing my bets then my arm and head started really hurting.

My arm continued to hurt the next few days, but I refused to get it x-rayed believing any broken bone would just go away. (I could just take a Flintstone vitamin and some ginger ale.) Eventually, I did go and get it x rayed. I prayed that, for once, God would not give me a break. They took two x rays; one showed it could be broken around the elbow and the other showed there was no break. The doc says they typically take that to mean no break. Finally, I get a break, at least until I get the bill.

There ought to be some universal law of nature that if you're in a wheelchair, no worse can happen. Falling should be outlawed for the disabled. They already have enough crap to deal with. They should only have to contend with the trials of cutting their toenails. The ironic thing was that I was on my way to church. Really, God? I could see Him bushwhacking me if I was heading on out to the strip bar, but Father Mahoney's Saturday sermon? I wonder what that was on "How God Always Watches Over Us" or "God Can Get You at Any time For Your Sins." Well whatever, I took it as a sign that I had God's blessing to stay home and watch the Auburn football game, which I lost twenty-five bucks on. Thanks again, God. I'll be taking that out of the collection basket next mass.

Unfortunately, every day in a wheelchair is not a day at the beach. I am thankful that the falls are few and far between. There's only so much metal they can put in my body. I think the worst thing about the whole ordeal was there was no excuse for it. I was perfectly sober. ■ABILITY



by Jeff Charlebois

冼保康 无声之地，妙手匠心

Xian Baokang: A Violin Craftsman in a Silent World

The results of the Violin Society of America (VSA) international competition in November 1998 came as a shock: The higher-than-usual judging criteria had cut the list of winners so short, that many hopeful candidates from Europe and America did not make it.

Three that won the certificate of merit for tone were listed alphabetically by their family names: Guangyue Chen, Jeffrey Robinson, and Baokang Xian. The first was an American-Chinese violin maker living in Houston. The second doesn't look like a Chinese. The third, apparently a Chinese, was barely known among Chinese instrument lovers in the American-Chinese community.

In the meantime, the man by the name of Xian was taking his busy shift in the Radiation Department of the Hebei Medical University Fourth Affiliated Hospital in Shijiazhuang City, China. It was days later that he was told the news by a friend who had heard about it by chance while in the US. Months later, Xian sent out a letter of self-introduction to the US-based international society for instrument lovers.

Making the best violin for Mother

In 1955, Xian Baokang was born in a "happy family of intellectuals". His mother, a graduate of the Central Conservatory of Music, had studied with the distinguished violinist Ma Sicong. His father, a proficient speaker of English and Japanese with some experience in painting and also violin, enrolled in what is known today as Hebei Medical University (formerly Hebei Medical School), before moving on to further studies in Japan. However, such talent genes did not await little Baokang to catch before he lost his hearing.

Over a year after birth, Baokang came down with measles and a persistent high fever. An overdose of streptomycin left the baby permanently deaf in both ears, as the husband of his father's sister found out one day by tapping the chimney hard, to which the boy beside him paid no attention. "Oh no. Not deaf, I hope!" It was only then that the couple took their son to Beijing Children's Hospital for an examination. It turned out that the boy had lost a considerable amount of hearing for high-pitched sounds and that only some parts of neurons for alto and low pitch were spared. It was a time





Xian Baokang Violin Craftsman

when semi-conductive hearing aids had not yet been available in China. To learn speaking, the family tried everything they could: lip-reading, gesturing, and placing the young boy's hand at the corner of his mother's mouth to let him feel how much air flowed – all was to little avail.

Baokang's childhood memory includes many a time when he watched his parents' violin duet, the strings simmering in soft light to emit long winding sounds. Unhearing, the boy would turn attention to his own play, but the connection between him and the violin started very early. In 1964, the nine-year-old Baokang finally had hearing aids that his father bought from a Japanese friend. After that, he started to learn, speaking slowly, and to reenter the hearing world.

However, gloom and light may take turns on one's life. The onset of the Cultural Revolution in 1966 was inescapable. Fictitious labels of "Japanese spy", "reactionary academic dignitaries" and "the offspring of reactionary capitalists" embroiled Xian's family in a thorough household raid. Almost everything was confiscated, and the most painful of all for both Baokang and his

mother was the loss of a violin.

It was a precious Italian violin of more than three hundred years. Her father traded four and a half gold bars to get it. This instrument became her favorite, but even after the political redress in 1969, she was not able to find it back. Baokang sensed his mother's emotional switch – She had become quieter and would very seldom play violin. The young man wanted to make his mother happy. The loss of hearing had led him to acquire more skill with his hands, eyes, and his mind. He had always enjoyed handicraft and thus started to try to make violins. Inwardly he vowed to himself that he was going to make a violin exactly the same as the one his mother had lost.

Opening a violin shop in the sun

In 1973 Baokang's father, looking at his son's unstoppable enthusiasm to balance his high school career and violin craftsmanship, hired a professional maker in Beijing. Having learned with the master for a while, the teenager completed his first violin on his own. With excitement, he showed it to his mother. "How do you think I did?"

“Quite good. Not bad.”

“How is it compared with that one of yours?”

“Haha! Not even one hundredth, maybe less.” His mother gestured the gap with her hands. “But your first one was no easy work to make.”

After graduation from high school, Baokang spent three years honing his skills as a violin maker from home. His parents, however, hoped that he would have a secure job for a living. They managed to get him three jobs in a row. By 1998, Baokang had worked in the Radiation Department of the Hebei Medical University Fourth Affiliated Hospital for 15 years. Despite the busy three work shifts, he still managed to make time for craftsmanship and competition. From 1986 onward, his violins started to be sent to compete in France, Italy, and the US as he wanted to have his work acknowledged by the most distinguished body of accreditation.

Finally, the 1998 VSA competition gave him a shot in the arm. After that, he resolved to quit his job at the hospital altogether and open a violin shop. What seemed to others a crazy move was only a natural step he felt he must take to advance further. Behind him lay numerous products he had crafted and all his violin-related memories, the fondest being of his parents playing duet, followed by the devastating Cultural Revolution at age 11 and a yet unfulfilled promise he made to his mother when he was 14.

From then on Kangbao started to absorb every minute detail he needed to know about making violins. He would study each and every fine violin he had fabricated. Whenever he got the chance, he would lose himself in it, disassembling, taking notes, and mulling over data from each part and hues on each surface. In the world of violin making, he had found the source of a desire for self-realization.

In 1999, the Xians’ Violin Shop was officially opened to the public, marking the earliest establishment of its kind along what would be gradually taking shape as the Street of Musical Instruments in Shijiazhuang.

The northern Italian city Cremona is known as “the hometown of violins” producing the world’s best string instruments. Pretty much like a child, Baokang is fascinated by the old Italian violin shops and sun-basked streets. In his own shop hangs a painting that depicts a few violins dangled under the sun in a courtyard. When he came back from Italy, he set off to make his shop a replica of its Italian counterpart.

A step into the shop would immediately shun out the noisy street. About 30 square meters, this store is divided into two parts. At the front is a neat exhibition space where the sole protagonist is a violin hung up high. At one corner sits a phonograph with a display of violin

making books and vinyl records. Towards the back is a smaller work studio with a wall of tools attached in a haphazardly looking but well organized manner. On the right hand is the owner’s workbench. Such an exquisite and affectively alluring design it is.

Most visitors come to get their violins fixed. They bring their instruments in, reporting the problem as they take them out. Baokang fixes his gaze on their faces as his way of showing respect and reading the lips. Sometimes he gets it all wrong, but he loves to share anything about violins time and again. He would repeat his answer exactly to the same question as he did minutes ago, refusing to leave out any particulars.

Each violin is a child in his eyes. He would wag his finger at once whenever he found the client holding the instrument in a wrong position. When in high spirits he would take out his violin and play; the hearing aids behind his left ear would look as if it was hiding away.

Austere, classical, rigorous, neat

“Austere, classical, rigorous, neat, clear-lined, not to show the traces of a rigid workmanship, but rather a spirit of flexibility,” reads a motto that Baokang handwrote for himself and placed in the studio. “By way of these competitions, I hope to make more people understand that there are also good violin makers in China.”

The winning violin of 1998 became the subject of a generous offer, which Baokang declined. The VSA upholds the rule of anonymity throughout the competition with such rigor that even the labels of the competing violins need to be covered up with brown paper. The performer is asked to play the same musical piece with these violins. Judgement is to be made on workmanship and tone for the commendation of gold and silver medals as well as certificates of merit for workmanship and tone. People who had learned about his hearing conditions could not believe it. “You have something up your sleeve, don’t you?”

Baokang’s possession includes a French violin labeled 1798 – as old as the Italian model his mother used to have. His father bought it and fortunately, it survived the Cultural Revolution. “I have opened it twice. French violins have their own style and I examine and feel it every day.” About each observable piece, he keeps a detailed record. With these close observations, the violin seems like the craftsman’s primary teacher who would, inevitably, influence his caliber of making violins. From the very first beginning Baokang had an up-front view of “high standard.”

As a Western musical instrument, tuning the violin can be difficult: the very fine nuances of each sound can easily go off course. Following the general framework, adjustment is essential when the assemblage of more than 100 parts has completed. Because of his hearing problems, Baokang has taken many detours in this



respect. Many things need to be taken into account, such as a shift of the local weather and the selection of the strings and bow. To determine if he hears it right, he has made himself acquainted with many violinists. "I will sort out my violins by tone and then ask the professional violinists to do the same after a go. If they put the instruments in the same order as I did, it means that my judgement is accurate." To ensure authentic and precise tones, Baokang has relied on this kind of external support for 40 years.

The violin maker had his own breakthrough when he finally took a leap out of mimicry as to what type of wood to use, what makes up a paint, and how much precision the tools should allow. With bare hands he could tell a 50-gram difference between two wood boards. An ill-fitting tool, he would tinker to his satisfaction. Over time through research he has figured out one thing or two about Italian paint formula. In his trade, Baokang believes that God disposes. Prior to work, he would be fully prepared and wait until he completely settled down with the sun in its prime. Whenever such moments came, it would feel as if the Cremona sun had shone

through his studio. All these years Baokang has kept driving towards an unwavering goal: To make the finest violin and win the VSA gold medal.

Father loved Beethoven's D major and Mother, Tchaikovsky's, two pieces which Baokang often plays on the phonograph, though he can't hear the higher pitches. All sounds higher than the fifth position, he is unable to hear, but he has examined and observed the structure, running-in, and change of over 100 parts in a violin. He has seen fine instruments that produce extraordinary sounds. In his heart a violin has long been made and it is exactly the same as the Italian one his mother once had. ■ ABILITY



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

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A Blind Eye

I just returned home from a quasi-urgent visit to a cornea specialist. My optometrist has been treating me for some vision problems, including developing a haze over the center of my left cornea, which was distorting my vision.

The cornea is the clear center of the eye. It is the lens that allows light to enter the eye.

My vision issue started about three months ago and had cleared up with treatment for about a month. Three weeks ago, it started again and this time it was much worse. The hazing is not getting better and distorts my vision, as if I was looking through a piece of wax paper or as if I smeared Vaseline over my eyeball. In the





bright daylight or when I get flashed with a headlight, it is impossible for me to see anything at all.

I suppose the urgency my optometrist felt, warranting an emergency visit with a specialist, was the fact that I leave at 4:00 am the next day to speak at a MS patient educational event in Tuscaloosa Alabama. I am riding my motorcycle of course, and it is 1300 miles and about 20 hours to ride from my home in New Hampshire.

Dr. Keith Emery is my optometrist, and I can understand his concern for my health as well as the trip not making the issue worse. He pulled some strings to get me the appointment. I don't blame him for not wanting to be responsible should my condition worsen while away, or if riding 40 hours in just a few days might do irreparable harm. Eyes are sort of important.

Elin, my wife was also concerned about my traveling. I have been having problems seeing for the last few weeks and because of some remodeling work I was doing around the house, I was also suffering from carpal

tunnel syndrome in both wrists, causing my hands and fingers to be tingly and numb. Between needing my hands to hold the handlebars and my eyes, sort of important to drive, I did not blame her for wanting to hear I was medically grounded.

The cornea specialist was pleasant and went through a series of questions and vision tests before looking at my eyes with her special optical microscope-ish contraption.

“Oh, Boy”, was not the phrase I was hoping for. Apparently, the haze was completely covering the center of my left cornea and I have additional scarring that may be new, some weird nodules around the rest of the cornea and some developments in the other eye as well.

We discussed my having MS, my heart issues, my medications, my spending 20 hours a day with my head in the wind, and my recent couple of weeks working on retiling my basement. I thought maybe some of the concrete grinding or mixing of mortar might have caused



some irritations, but the doctor did not seem to think so. This type of hazing can sometimes be caused by a virus, but she did not think that was the cause for my vision loss either. She was going to request my past exam records and try to figure out what it might be. I was prescribed some steroid eye drops and given a follow up appointment for next week.

I may not be able to see very well, but I was not specifically told I could not drive or ride my motorcycle to Alabama. Because the eye condition is not from my Multiple Sclerosis, not from riding long hours on the bike, not from cement dust and not from an infection or virus, I have decided I'm not going to bother worrying about it until I get back following week. I picked up my prescriptions and a cool eye patch at the pharmacy, booked my hotel for tomorrow night and packed my saddlebags.

Patients are expecting me in Alabama and my mission to ride a million miles for MS doesn't get sick days. Riding a motorcycle is therapeutic for me in many ways, so as far as my latest health issue is concerned—

Out of sight, out of mind. ■ **ABILITY**

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Gale Buchanan

Everyone Needs to Eat!

Recently, U.S. Department of Agriculture made a controversial move to relocate its Washington, DC offices of Economic Research Service (ERS) and National Institute of Food and Agriculture (NFIA) to Kansas City. Secretary of Agriculture, Sonny Purdue, attributed the move to a cost cutting measure as well as a move that should bring USDA scientists closer to agriculture and research. Good idea?

Many disagree. Farmers and researchers alike have been critical of the move since the USDA works to inform Congress on legislation and appropriations. Additionally, many are worried since two-thirds of the 500 USDA employees are choosing to leave the USDA rather than relocate, causing a massive loss of talent. Many opponents of the move see this as a war on science.

All this comes at a time when farmers are living in uncertainty. Tariffs are causing lost markets abroad and lost income at home. Unusual weather patterns are leaving hundreds of thousands of acres of flooded farmland, much of which goes unplanted. Farm bankruptcies are rising.

During this critical time for US agriculture, *ABILITY's* Shelly Rohe and Chet Cooper met up with Gale Buchanan, former USDA Chief Scientist during the G.W. Bush Administration, to gather his thoughts on science in the world of agriculture.

Cooper: Gale, give us your views on what's happening today and why agriculture and trade are so important.

Buchanan: American agriculture is greatly dependent on our export markets. Anything that does anything to hamper trade of our commodities certainly puts a very serious—has a very serious impact on the farming community. So many things—not just grains, but a lot of the meat—are all important.

Cooper: With the trade wars that are happening right now with China, for example, how does that affect a farmer or just the industry itself?

Buchanan: Of course, the markets are greatly dependent upon how we move commodities internationally. So, the price of soybeans and the price of corn are affected by

how the markets are doing. And of course, that trickles all the way back to the farmer who actually produces them. Anything that happens that affects the markets in any way, the ultimate people who have to bear the brunt are the people who are producing the commodities. That's why it gets down to the local farmer very quickly.

Cooper: Knowing that there will be continued tariffs added at different times and not having stability, does that affect it somehow? Lack of stability in production or orders?

Buchanan: Part of the problem is the certainty, not knowing. Farmers do have some flexibility in the products they produce. Of course, they're fixed in some ways. If a farmer has a cotton picker, they've got to plant cotton because they can't pick corn with a cotton picker and they can't go out and buy a corn picker. The problem is agricultural production is limited in the number of crops you can grow, but they have some flexibility. But when you have uncertainty, flexibility doesn't make any difference because you don't know what to do.

Cooper: So you're a professor? Do you teach now?

Buchanan: I was a professor at one time. I've been an administrator for the last 30 years.

Cooper: And you were teaching—?

Buchanan: I was a weed scientist.

Cooper: Oh, and it's legal in California now. (laughter)

Buchanan: No, not that kind of weed.

Cooper: Speaking about that, what do you think about what's happening with the spread of pesticides moving into other crops and how that's playing out?

Buchanan: Well, I wouldn't want to comment on—I've been involved in herbicides as a useful tool for the past almost 50 years, and there's probably no area of science that's been more researched than the use of weed killers. And of course, we like to think that we do all the research that's necessary to ensure the safety. For example, take another class of pesticides, insecticides. Research that showed that you didn't need to use as many insecticides to control boll weevil has had a great impact on that problem. Where they used to have to spray boll weevil 10 or 15 times in a season, the boll weevil eradication problem developed research that reduced that need for insecticide for boll weevil control to two or three applications per season.

Cooper: We're talking about cotton now?

Buchanan: In cotton. And there are other examples.

Research in pesticides has been very definitive, and I would like to think that they're safe. I don't hesitate to go into the grocery store and buy any fruit or vegetable. I have confidence in our system. I certainly wouldn't go in and buy something that I thought was going to kill me.

Cooper: The reports are coming out now that there was evidence that was not being taken up by both the Food and Drug Administration (FDA) and the Department of Agriculture about this leakage into other farms, other property. I'm calling it "spillover," but it's airborne. I'm forgetting the name that they're call it. And that it's causing—I think it was Monsanto. Do you know the more current news of what's happening with this?

Buchanan: Roundup.

Cooper: Yeah, Roundup. What's your thought on that?

Buchanan: Well, I would not want to speculate. I've used Roundup when I was a researcher from the day it was a numbered compound. I've used it in many different experiments. I've worked with it. But the lawsuit that's pending I would certainly not make any comment either way about something like that.

Cooper: It's in litigation right now.

Buchanan: But I do have confidence in our system. I think our system is very sensitive to trying to do what is best and protect the American people. I don't think anybody wants to do anything that would cause any harm to anyone.

Cooper: Speaking to the system, the system is part of an ecosystem which connects to the climate and such. What are your views on climate change and what could happen with farmers if climate change continues to move forward?

Buchanan: Climate change is certainly a hot topic now, but probably no one would be more impacted than agriculture. And for many years we've been involved in research that tries to address—because we've got to ensure productivity, regardless of the climate—We have to deal with the weather all the time anyway. Climate is just an extension of the local weather to long-term. So, obviously we're concerned about climate change.

One can't argue with things that are happening. You might want to argue about what's causing it, but it's hard to argue with polar ice melting, icebergs melting, things like that. You can't argue with it. So, I don't know what the big deal is. We need to continue doing research and continue looking at how climate affects our productivity of crops, but I don't think you can argue with the fact that things are happening, that we don't know exactly what is the cause of.

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Rohe: I'm from Minnesota, and I see a lot of the local farmers not making quite as much, so they're repairing equipment, not buying new equipment. Has there been any research on productivity due to faulty tractors and combines or not having new equipment they need?

Buchanan: Of course, anybody knows that when you have good prices for communities on the farm, that's when you buy equipment. Farmers are notorious for "if they ain't got the money, they don't spend it". They patch up the old tractors. Whether that impacts productivity, I honestly don't know. I rather think that most farmers ensure that even though the old tractor is patched up, that it's going to continue. But I don't know that. It's a good question, though.

Rohe: With the tariffs, people aren't buying as much of the equipment that they might ever buy new, so they're trying to repair what they can?

Buchanan: Yeah, absolutely.

Cooper: John Deere and companies like that are not happy that they're just repairing and not buying new.

Buchanan: They're tied totally, inextricably with agriculture. They might sell road grading equipment, but they're not going to sell any farm tractors and cultivators and sprayers and that sort of thing when commodity prices are very low. I visited the John Deere plant in Molina, Illinois, earlier this year, where they make combines. A combine for a million dollars, that is a lot of money. You've got to have a decent price of wheat if you're going to pay for it.

Cooper: Where would you invest, soybeans? It's a joke.

(laughter)

Buchanan: I don't think I'd buy any soybeans right now.

Cooper: If you were to tell somebody going into—let's say it's generational. You hear this happening often where the young generation of a farmer says, "I'm getting out of this. I'm going to sell out to a bigger place or I'm going to close up or sell the land to a developer." What would you say to that generation that is thinking about that now?

Buchanan: One of the facts you can't argue with is that

farmers are getting older by the day. It's so difficult to get into farming, unless you inherit land or marry someone who did inherit land. But for a young man getting out of college with a student loan to go down to the bank and say, "I want to borrow \$5 million to buy some farmland," people would laugh at you. It's very hard to get into farming.

There's a future—the one thing there's no exception to [is] there's not a single person on this planet who can survive without eating. So there is going to be a need for somebody to produce food. And it's got to be such that we produce food for the entire world. I wrote the book *Feeding the World: Agricultural Research in the Twenty-First Century*. Agricultural research is clearly a fundamental basis that ensures our survival on this planet because research is what ensures the success of agriculture. I hope you go on Amazon and get my book and read it.

Cooper: What are your thoughts about these new companies that are producing plant-based meat type products, like the Impossible Burger?

Buchanan: More power to 'em! I bought an Impossible Burger, and I wasn't sold on it. It was a little thin piece of meat about that thick (gesturing ¼ inch width). Tough.

Cooper: Too bad! That's a typical Burger King burger!

Buchanan: Burger King does a pretty good job with plenty of mayonnaise and mustard and lettuce and tomatoes, you've got a good sandwich without any meat. (laughter) I was not sold on it.

Cooper: So, you haven't had a real one, then? Cooked at a restaurant? I've eaten in several different places, and if they're not prepared by a good chef, a good cook — The first one I had was the best, and I go back to that one. It literally bled. It was just like meat, the texture, everything. And other ones I've had, there was one where I thought, "This is rubbery. This is not good at all." They just didn't know how to prepare it.

Buchanan: More power to 'em. As long as it's nourishing and edible, fine. We grow plants, too, in agriculture. You don't pull that stuff they make those Impossible Burgers with out of air, do you? It's from agriculture. What's the big deal?

Cooper: Absolutely! I was just wondering about that connection where we try to produce less beef and more plant-based products that at least for a lot of our palates, we can think in our brains—is it working on steak right now?

They're having some problems with gristle, making it feel the same as a steak. Do you find that agriculture, because of the wheat and everything that cows eat, is

that connected to raising cattle in agriculture? Or is that something completely different.

Buchanan: Oh, yeah, that's part of agriculture, of course.

Cooper: What do you think about the issues of all this beef that's being produced and should we start reducing that to whatever degree we can?

Buchanan: Oh, I think whatever the market will determine if it's acceptable.

Cooper: So you think it's more market-based rather than trying to restrict it?

Buchanan: Sure! I eat salads every day for lunch. That's the only thing I have for lunch. I love salads. My wife and I eat a lot of beans. But we also like meat. There's room for all of these products. If it tastes good, it's competitive, go for it. And being in agriculture, I don't have any problem at all with baked beans.

Cooper: What about fake news?

(laughter)

Buchanan: I don't like fake news. Like I told my wife after I got back from eating at Burger King, the way to test it would be to pull the meat out and put it on the plate. She likes to have her hamburger without the bun, without the lettuce, just the meat. I said, "That'd be a very poor meal." Maybe if they're cooked like you said, it would be good.

Cooper: You've got to try that. That would be a fair test for that.

Buchanan: I don't have any problem with it.

Cooper: What was your title back in the day?

Buchanan: I worked for the Bush administration. That's why I'm here, for the union.

Cooper: Which Bush?

Buchanan: Bush 43, George W. Recently. I ain't that old! (laughter)

Cooper: Will he be there?

Buchanan: Yeah. We have a reception tomorrow night.

Cooper: Darn! Every time I come to DC, there's always something where I say, "Oh, I missed that!"

Buchanan: Where are you guys from?

Cooper: I'm California, Shelly's from Minnesota.



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Buchanan: What do you do in Minnesota?

Rohe: I work for *ABILITY Magazine*.

Buchanan: How do you know farmers?

Rohe: I've got a lot of farmers in my family, a lot of dairy farmers.

Cooper: No dirt under your fingernails.

Rohe: A couple of crop farmers, but mostly dairy and beef. I had a big family dairy go under this year because the snowstorm hit. The snow was so heavy it crashed the roof of the barns. That particular storm killed a lot of cattle in the area. I don't think they lost anything, but they had to sell.

Cooper: Wow.

Rohe: Some farmers have a hard time paying for repairs.

Buchanan: I went to school at Iowa State, and I had a good friend from Pipestone down in southwestern Minnesota.

Cooper: Did you know Senators Harkin and Grassley?

Buchanan: Yeah.

Cooper: They care about the farmers, too, that's for sure.

Buchanan: I'll tell you, the area you're in is very important because agriculture needs to get its story out.

Rohe: I agree.

Buchanan: People don't realize, this country's been blessed. The problem we have is too much food. You go into a grocery store, and you've got a thousand different boxes of cereal, but that's not the case all over the world.

Let me tell you something. We have got to ensure by some means—and I don't know how to do it—but everybody's gonna have to eat. If we think we've got a little problem with Mexicans and Central Americans coming across the border, you wait until the world is hungry. What are you going to do if there's a huge ship that comes into New York harbor with 10,000 people on board? What are we going to do?

Cooper: And there'd be more than one if they're hungry.

Buchanan: It'd be more than one. Everybody's got to eat. I don't think we realize that yet. ■ **ABILITY**

Tanna FREDERICK

Home Is Where the Heart Is

Tanna Frederick is best known for her stage and independent film career. However she is also a writer, producer, marathon runner and the founder of “Iowa Independent Film Festival”. She is also co-founded the “Project Save Our Surf”, dedicated to ocean conservation, with a deep connection to surfing.

Her new movie has a lot of personal connections. She has dealt with clinical depression, and her parents also have been involved in the world of mental health, including working with the organization National Alliance of Mental Illness (NAMI). Tanna took the title of her film to heart and decided to film *Two Ways Home* in her home state of Iowa with several scenes being shot on her real-life grandfather’s farm. *ABILITY Magazine* caught up with Tanna after her return from Switzerland where she was shooting her latest indie film. This interview is about *Two Ways Home* life on the farm and the importance of raising awareness around mental health.

Melinda Chilton: Congratulations on the movie.

Tanna Frederick: Thank you so much!

Chilton: We have something in common. I was born and raised on a farm in Illinois.

Frederick: I saw that! I’m like, “Oh, she’s a small-town girl.” I saw on your IMDb page it talks about how you grew up in a town that was, like, two blocks wide. Oh, girl! She grew up in a small town, too?

Chilton: And my parents still live there on the farm. My dad just turned 81. He still goes up and throws hay down.

Frederick: Oh, my God!

Chilton: And you shot this movie on your grandpa’s farm?

Frederick: I did! I was like, “Oh, so she gets it!”

because I just wrapped a movie in Switzerland and now, I’m in a very, very small town in Iowa called Osage and just kind of recouping on a farm—

Chilton: Osage County.

Frederick: —with my dog.

Chilton: Aw!

Frederick: And just chilling, I’ve been in the Alps on this insane film set, and so I still have a house in Iowa in addition to living in LA, and my whole family’s here, too. So, when I get done, too stressed out, I come out here and just hang out.

Chilton: Oh, I know.

Frederick: It’s fall here, the pumpkin patches.

Chilton: Oh, I’m so jealous! I was like, “I’m going home to the farm to recharge my soul, I’ll be back.”

Frederick: Exactly! It’s so necessary, it’s so important, especially when you grew up in this area and you need the chilling out, the fireplaces. But I have the best of both worlds I have a farm in Iowa and live in LA, both. I have two wonderful worlds. I really feel blessed like that.

Chilton: And tall redheads.

Frederick: Oh, yeah, that’s right! That was a cool thing I saw, too. Bravo!

Chilton: Yeah! I ran into Jane Lynch and I told her that the casting director said I was too tall to be an actress. And she’s, like, six feet tall. She was like, “You tell them I said you can do anything.” She was a little more colorful about it.

Frederick: (laughs) Thank you, Jesus, for that!



Chilton: And how tall are you exactly?

Frederick: I'm 5 foot 8.

Chilton: I'm 5 foot 12.

Frederick: Oh, my Lord, I love you! That's amazing, and a redhead. It's true, though. There is a lot of casting directors who will be like, "You're too tall, and you're a redhead." Although the red-headed thing is now popular but when I moved out to LA, I remember that they were like, "Sorry, you're not a blonde or a brunette. Good luck."

Chilton: Now it's the redheads.

Frederick: It's only redheads.

Chilton: Yeah, finally! Let's talk about the movie, how did you pull this together? What was the start of it?

Frederick: Well, I wanted to film a movie in Iowa using my home state and local talent and local crews and keep it true to the state after moving to California. It was a pet project to utilize the state and showcase the state. That was definitely an objective when I began putting the project together. I had a script from a family friend—it was loosely based on my grandfather, who was a World War II vet, and his difficult cantankerous personality. With several modifications to the script and different iterations, it grew and ended up being a film about something that I had always wanted to cover with a mental health undertone. In terms of the woman confronting bipolar as part of the adversity and the journey that she was on with the grandfather also having PTSD from his World War II experiences. I've been so pleased and very elated with the fact that first of all the film is even finished, and then that it's been doing so fantastic on the festival circuit.

Chilton: I have watched the film, and I loved it.

Frederick: Oh, thank you for watching it. Thank you so much.

Chilton: I didn't know what to expect. I was told we were going to interview an actor/producer. You know how Oprah reads the book for her book club; I watched the movie.

Frederick: Thank you for doing that.

Chilton: I was like, "Oh, my gosh, if I had known it would be this good, I would have had a movie night with popcorn and the works!"

Frederick: Oh, thank you, Melinda!

Chilton: The production value, the acting, the casting, kudos to the casting department. It was so well done. I

was extremely impressed. It took me on a journey, a trip. I felt for your character, Kathy. I really felt for Kathy. It was such a raw truth, your performance. How did you approach the character? It really brings it to life. I felt like I was watching a real woman struggling with a real issue in her life.

Frederick: Thank you so much for saying that. That was what I wanted to portray, a real woman with a real story. Doing that, getting a real person with a real story, it sounds so easy, but it's so much more difficult than it sounds. It comes down to getting into the specifics of storytelling as far as an actor and a storyteller. The more detailed you can get in a story and in a character's portrayal of something, I think that's where it becomes more accessible to people. In this particular character's story, she's dealing with bipolar illness, but she's also dealing with family. I think dealing with mental health issues in a film, you have to be mindful. This movie took seven years to complete.

Chilton: No kidding!

Frederick: Yeah, with the budget, with all the in-kind favors that we pulled, it was a labor of love, as many films are. Thank you, Jesus, that it got finished. What I really wanted to do, because I was involved with mental health since I was a kid and the beautiful work that my parents did. I wanted to have something that really broke down some of the stereotypes that have been involved with the stigmatization of mental health in the media. I wanted to have a piece that people walked away from feeling not only proud of what they've gone through, but I wanted them to feel more whole as a human being; faced with adversity through confronting mental health disorders, whether it be through their own family or through their own experience with it. I wanted this film to help spark open dialogue within families and within people's own selves. Playing on the festival circuit, this has been a really cool experience. We just started on our festival roll, so I guess the biggest indicator is, is this creating something artistic that is healing?

At the Q&As people are coming up to me and saying, "Wow, I've felt that way. When you looked into the mirror, I felt that character was very authentic and that look, I've looked at myself in the mirror and I've had that specific look. It's not something I could express ever in words, but through this film, I understand, I know that feeling." That's the neat thing about art, that we can put into pictures what can't be expressed in words or perhaps with a therapist sometimes. As an artist, I ask myself "How do I create something that will make people walk away feeling empowered and feeling somewhat healed or closer to their family members?" That's been so important to me, because growing up, I watched so many people feel so ashamed about their condition or people feeling angry about other people's conditions or people not wanting people living next to them. My parents were involved in in this transition



Tom Bower in *Two Ways Home*

center which they created in northern Iowa, where they would take mentally ill individuals off the street and help to get them into therapy, help to get them on the correct medications, help to integrate them back into a job so that they could be working into apartments, get them back in touch with their relatives if that was at all possible. Watching people I know, watching society cast them out, people not buying houses next to this transition center. And you know, coming from a small town—

Chilton: Right!

Frederick: —how much anger and misunderstanding differences can create was a big eye-opener for me as a kid. So, this has been a goal for me, to create something that could stop this misunderstanding or show a real person dealing with a real thing, which is mental illness.

Chilton: I think you *definitely* accomplished that with this film!

Frederick: Thank you.

Chilton: What I really loved, what I found interesting about your film—Kathy had bipolar and you see her struggle. You give an honest voice to it. What I found also deeply important was, as you mentioned, she's surrounded by characters who are trying to also accept that she has this illness and what that means in their lives and how to deal with it. Everything from her daughter to her grandma to the aunt to Junior. I loved the scene between you and Junior in the barn, where he basically has a snap judgment of, "No, I'm not doing this."

Frederick: Oh, thank you!

Chilton: I see people do that. They look at mental illness and it's scary, it's bad, it's dangerous. Or maybe this person's just being irresponsible, should get their act together. I grew up with some family members who had mental health issues and I've seen when they have the proper medication and are being taken care of and having a loving support system, and I've seen it when it's not. And it's very different.

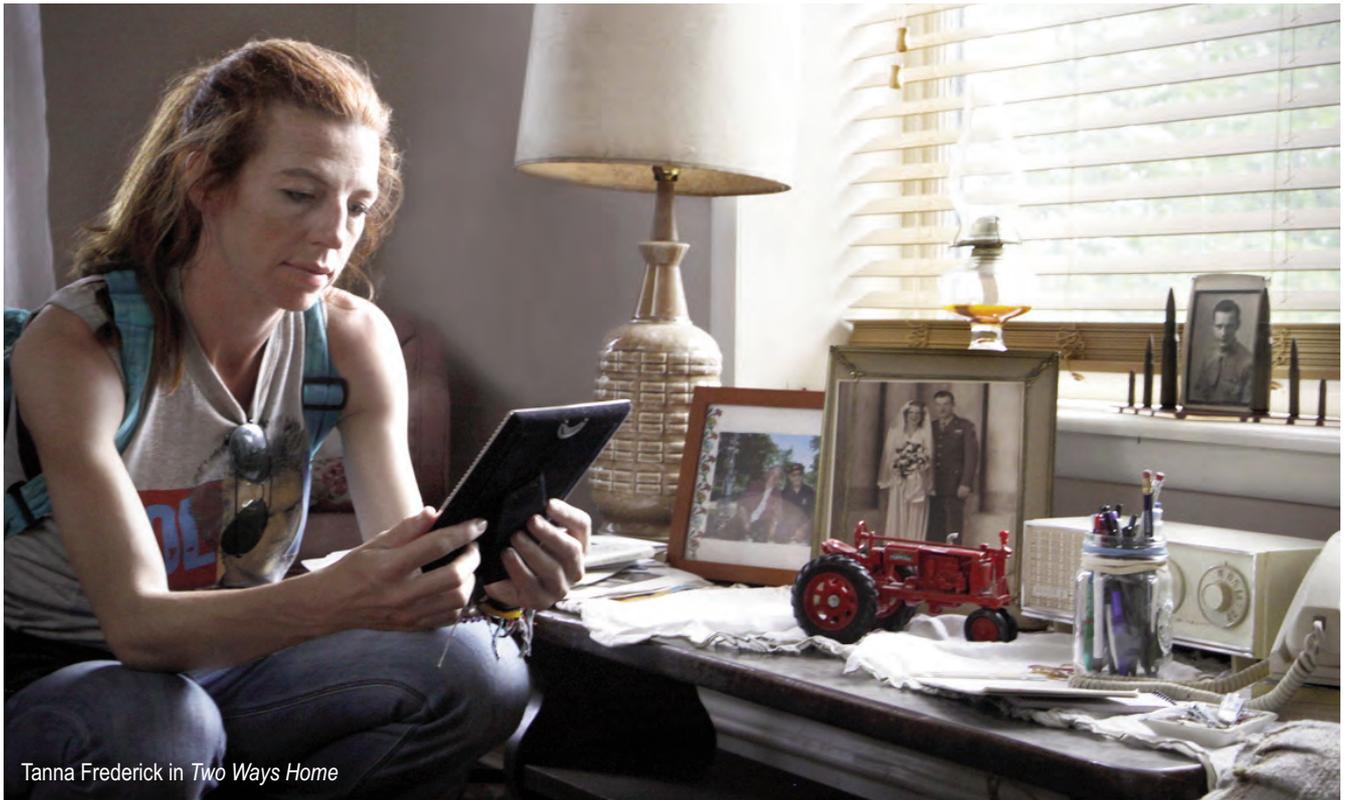
Frederick: Absolutely.

Chilton: Mental illness can seem very scary and dangerous. What would you say to people who are having a moment that Junior had in your film, in that barn scene?

Frederick: It's unfortunate, but it is such a catch-22 in our society, we really are so far away from accepting and recognizing that mental health issues exist and are prevalent, just like diabetes, just like cancer, like hypoglycemia. And then in so many varying degrees. We don't acknowledge post-partum as much as we should. We don't acknowledge seasonal affective disorder, the varying degrees of depression, anxiety disorder. They're just not understood. They're not as easy to put your finger on in our society as much as something like being lactose-intolerant is. (laughs)

Chilton: Whenever someone has a problem with a mentally ill person and they make them feel guilty for doing something wrong, I'm like, "Would you give this same attitude to a person with breast cancer?"

Frederick: Yeah, exactly. I think that was the most important line in the movie, when the grandfather says, which is great, to have that coming from a grandfather to the granddaughter, saying, "Would you withhold



Tanna Frederick in *Two Ways Home*

insulin from a diabetic?” That understanding multi-generationally in the movie in that relationship was utilized really, really well on so many different levels. I think also as a kid, throughout high school, I worked in my dad’s pharmacy. I watched different degrees of people who were ashamed to say that they were on medication not just antidepressants, but people who were severely mentally ill. People being so awkwardly devastated from trying different meds, so bravely going through this challenge of trying to find medications and understand their conditions in a society that completely degraded them and their condition. They were coming into the pharmacy and saying, “This is dry mouth. This is not working. I feel so much more myself when I’m off.” To not have the help, the other support of people. I mean, it’s not a matter of congratulations, but in an ideal world, in my ideal world, it would be almost a congratulatory system, like, “Good job! Way to go, way to keep trying to understand what’s going on in your neurotransmitters.”

Chilton: Exactly. It’s a personal victory for each individual on their journey that should be celebrated.

Frederick: Absolutely. When we’re understanding so much about our own physiology and our diet and our bodies and then we’re just both still not adept at understanding what’s going on in our brains. It’s mind-blowing in a way, not to put down where we’re at as human beings, but it is a little bit shocking.

Chilton: I find it very shocking, right now, where our country’s at today, there’s a lot of talk, a lot of things

going on around discrimination at many different levels, against many different groups of people, and I hate to say “groups”. I wish we could just all be one big group together. But what I find ironic about it is discrimination against mental illness. You just can’t deny it. You can discriminate against it all you want, but the fact is that mental illness does not discriminate against anyone. It doesn’t care where you went to school, what color your skin is, what your sexual preference is, what religion you have, where you grew up on it. It wants to come into your home. It will come right in the front door, sit on your couch, and ask for a cup of coffee. (laughs)

Frederick: That’s a wonderful point. In the movie I was happy that we also explored the mental health aspect of post-traumatic stress disorder with World War II. Again, it’s something that only up to, like, five years ago were our veterans from Vietnam recognized, welcomed, which was a huge deal. My dad fought in Vietnam, both my grandfathers were in World War II, and to watch a lot of the vets going through so much PTSD, not only were they confused about where they stood and where people stood with their service, they were still experiencing trauma with loud noises, night sweats, physical and mental repercussions from fighting that war and then finally having the country say, “Thank you for your service. We’re going to start to erect memorials”. And not just that, but in Iowa, my dad—finally they wrote an article about his as well as other vets service, and I remember how much that changed him and changed his mindset. He experienced some physical changes. He went and got counseling. It was a big deal.

Chilton: Wow!

Frederick: But that also takes a lot. It takes a whole village to correct that mental health aspect of PTSD. It's something that's so hard to fight by yourself. It's a fascinating subject, and so even having that in the movie was pretty cool it was neat to watch the grandfather as he started dialoguing about it with himself in the journal. Something as simple as that.

Chilton: Yes. I thought it was really interesting. As I was watching the film, I was taking the whole journey with Kathy, and then you find out that Grandpa Walter has PTSD. I found that really interesting, and really great of the author to put those two together on the same trip. There's a wonderful scene between Kathy and her grandpa in the bathroom, the one outside, towards the end of the film is so touching and so real. The two characters help each other so much.

Frederick: Thank you so much. It was a really special relationship. I had that relationship with my grandfather with myself dealing with depression. On a strange level, it was myself dealing with depression and my grandfather dealing with PTSD and him being exceptionally closed off. Somehow, we were able to meet on a certain level, which I hope was captured in the movie a little bit, which I think it was, when I looked at it.

Chilton: God bless, your family for serving, and I'm so happy our country's turning around and welcoming all these troops home and given them the respect and the thank you that we should have been giving them a long time ago.

Frederick: Yeah, me, too.

Chilton: With that said, I remember as a teenager, I was at a lake, at a beach. There was a young woman there, maybe 15 years old. It turned out she had PTSD. She had a seizure, this whole thing, right there on the beach in her swimsuit. I remember she was screaming; it was so sad. I found out later she had a very traumatizing experience when she was about five years old, and she suffers from PTSD because of that. I found it interesting because we think PTSD is primarily soldiers, people who have served in the military, which I think is a big percentage of it, but it's also people who, like this young girl, something happened in her childhood.

Frederick: Yeah, it can be a car accident, there's myriad things that create PTSD. I think it comes down to the vocabulary of how you're wording things, because when you say "mental health," "Oh, that's a mental health problem," people are more reticent to deal with it and recognize it, even with the words "mental health". They're perhaps saying, "I met this five-year-old girl and she had—" whatever, she was in an accident, she had an incident when she was five and she was still traumatized. It's just there's something attached to even

the vocabulary that is used with mental health. But hopefully that's changing. I feel like it's changing, and I feel like we're growing. I don't think the film would be doing as well as it is without that change or not just my film, but this year particularly, Mental Health Week is coming up. Our film's playing at the Awareness Festival in LA. In May it was Mental Health Month, I believe. I think there's a growing cognition of how much change needs to happen. Fingers crossed. I think definitely, it's getting the attention that it needs. People are becoming more aware of it. I think that's great. People like you, who are given a voice, getting out there, making people more aware. But I think the more we talk about it, the more people are made aware of it, the easier it is to make that switch, to find a balance.

Chilton: Yeah, yeah.

Frederick: And I was in—not to go too much on a political bent and too far away from the movie, but it's really great also to see—I was at the Democrat wingding here in Iowa, and it was really great to see some of the candidates talking about our need to address mental health in the school system, too. Once again, it's not some sort of strange, out-there topic that we're dealing with. We're just talking about counselors who will be more available for kids who have myriad issues; bullying—A lot of kids are suffering from that. Or from the school shootings and what kids are suffering from that, how we need to have more people on hand to shape kids. Corey Booker gave a riveting speech about how the call to action right now in our country is to have more mental healthcare available to our teenagers at their most formative part of their lives and how there's a lack of that right now. I couldn't agree more. And that falls under mental health as well.

Chilton: Right. I love to hear that they want to get into the schools and talk to the young kids and all of us, hopefully by putting this subject out on the table for the young kids, the young people to talk about it, to hear about it. When they become adults, maybe that will help lessen that prejudice and fear and judgment around mental issues.

Frederick: Yeah, absolutely. And know that it's OK to be afraid or it's OK to feel different. That's completely natural. It's OK to feel anxiety. That's not something you need to hide. That just breeds more fear. And that's another thing that I hope to accomplish through the film, that this woman, at the end of the film, walks away through her trials and tribulations with her shoulders back and her head high because she faces adversity head-on and was basically just too tired to try to hide it or feel ashamed any more. Her objective was not about saying, "I'm not different," or "There's nothing wrong with me." Her objective was the bigger objective, which was her family, her love for her daughter, her trying to move forward in life. It wasn't about moving backward it was about moving forward. It made her a stronger,

more beautiful woman in the end. It made her quilt fabric more delicious and beautiful to have gone through the ups and downs of dealing with life and who she is as a woman and the emotional ups and downs. That doesn't make us ugly. And if it does make us ugly, as an artist, the beauty is in the ugliness of life.

Chilton: If everything was beautiful all the time, it would get a little boring.

Frederick: Absolutely!

Chilton: And everyone's idea of what beauty is is different. There's beauty in someone who came into your father's pharmacy and said, "You know what? This medication doesn't work. I'm ready to try something different. What else can we do?" There's beauty in that, in someone saying, "I'm OK. Yes, I need help, but I want to figure this out and I'm going to be fighting. There's something to celebrate about me because I'm fighting for this and I'm going to be OK. I'm standing up for myself."

Frederick: Absolutely. There's beauty in recognition of being different and showing vulnerability.

Chilton: It's who you are. "This is who I am today." And speaking about the children, I want to talk about Kathy's daughter Cori, played by Rylie Behr.

Frederick: Yeah, she's such a—

Chilton: She was fabulous! I don't know where you found that little girl. She really brought some layers to that character. Tell me about the journey, the importance of having that daughter there. She has quite a journey accepting a few things about her mom. When you're a little kid, you want your mom to be this perfect Disney princess, and that ain't gonna happen, no matter who your mom is! (laughs)

Frederick: (laughs) Yeah! Her character was so important for so many reasons. I think in this film especially, when you're dealing with a real family and a real story that I was trying to bring forth, that takes place in Iowa, that's not just some horror plex that's being made, but an actual real story that I wanted to show that I've seen people go through. Nothing will be bow-tied and wrapped perfect in the end. The struggle of this 13-year-old, whose mother isn't perfect, like you said, whose mother is bipolar and is what she makes mistakes but is trying to be a better person and to be a mother. How do you cope with that as a 13-year-old? Do you accept that? What do you do with your feelings, your angry feelings, your embarrassment? She represents the bouncing board of society. "Do I accept my mother? I can see very clearly that everybody else is not accepting my mother." She's an absorbing screen through which everybody's view of her mother was coming through this prism. At the end, was their relationship perfect?

No, and I was happy about that.

Chilton: Yeah, because who's relationship is perfect?

Frederick: Right, exactly. That would have been such a Disney version, without giving it away to people about the ending, but it was a very dynamic arc between Reilly's character and Kathy, my character. It's constantly in flux, but it's real, I think it shows what happens when a child has a parent with mental health issues.

Chilton: I had family members who dealt with mental health issues. The two in particular, they were already showing symptoms before I was born. So, I always knew them as who they were. And when I think back, I spent a lot of time with them. As a child, that was just my normal. I didn't have any judgment. It was scary, it was sad, I could see the struggle, not just for them, but for my family, but then I saw all these wonderful happy moments. That was my normal.

Frederick: Yeah.

Chilton: When I reflect back now, I find that interesting.

Frederick: What really is normal?

Chilton: Perhaps this is normal, if more people would give voice and not be ashamed of their illness or their friends' or family's, it might be a little bit more of the normal. It's normal to have colds and allergies in the autumn and the spring, so couldn't it be in the norm that we might have some other illness.

Frederick: I love that way of looking at things! I think that's really a profound way of looking at things. I agree with you. Once a stigma is removed, especially in a child's eyes, like you said, that was just a different option of looking at things.

Chilton: I never knew these two family members when they were quote-unquote "healthy." I never knew that. I only knew them after their symptoms showed up. To me, that was just who they were. When they'd babysit me, we'd do a science project in the kitchen. We'd make coffee, but they say it's Coca-Cola, and I'd say, "OK." As a kid, how fun was that? It was like every time I went to their house, it was like, "Let's pretend," and I didn't know that they weren't pretending.

Frederick: I love that! I love that! I totally hear you with that. One of my closest friends growing up was an older man named Larry, a beautiful, beautiful person. He had severe schizophrenia. The stuff that he did and he said shed so much light onto life for me. We would always have him over doing stuff, hanging out. I remember him sitting in the kitchen with me when my parents were out running errands, and he was like, "Why is everybody always disappearing? People will be in front of you one minute, and then they're just gone, into thin air." I knew



Tanna Frederick discussing *Two Ways Home* with her father

that that wasn't exactly—that he was maybe actually visualizing that, but at the same time, it made a lot of sense. I remember one day he said, "Yesterday I just needed to prove to myself that I could work, so I made sevens. I carved a box of sevens." He had brought over this box of sevens.

Chilton: Aw!

Frederick: And he literally took wood, he carved sevens out of wood, out of cardboard, out of plastic, just to prove to himself that he could work.

Chilton: And that's when you can celebrate with them, give them a big high-five and go, "Yeah!"

Frederick: Yeah!

Chilton: But some people will go, "Oh, no, put those away."

Frederick: Right. And when—like, with a female, when haven't we PMSed—

Chilton: (laughs)

Frederick: —and just tried to get through the day by doing laundry and eating chocolate and trying not to cry and watching *Friends* reruns? Is it really that different? No, it's not. If somebody had told me, "There's a strange man on your lawn and you shouldn't be exposed to that," I might have looked at that and been like, "No." But I looked at that as something magical, like, "Wow, this is a different way of looking at life!"

Chilton: I think we all, if you really think about it, have had a moment in our lives, if not a few of them, where we do feel like we could just have a nervous breakdown at any moment. We feel like we can't keep it together. It's part of being a human being. We've all been there to some degree. And if we can remember that, what it feels like, and know that some people feel that way every day, we could have some compassion for that.

Frederick: Exactly.

Chilton: I don't think we're as disconnected as we like to think we are. (laughs) From one another.

Frederick: No! Absolutely not! I think that's where the fear creeps in. The need to keep ourselves together prevents us from maybe saying, "Yeah, I spent all day yesterday making sevens." (laughs) Hypothetically, you know?

Chilton: You reached out to NAMI?

Frederick: Yeah, I did.

Chilton: Can you talk about that?

Frederick: Certainly. First of all, my parents served on NAMI and throughout my life my parents also were on the North Iowa and started and ran the North Iowa Alliance on Mental Health. They were part of NAMI and a North Iowa subsidiary. While I was doing the film, I wanted to make sure that I was not doing anything inaccurate for bipolar in portraying the character. In the media there are so many mis-portrayals of bipolar



Tanna Frederick and Melinda Chilton at the Awareness Film Festival

or different mental health portrayals.

What I really wanted to do was reach out to NAMI, so I called Mitzi Wright from West Side NAMI in LA. I also contacted once the film was finished some folks in Minneapolis with NAMI. My dream was to get this out and have it recognized as something that people could watch and as a learning tool or a communication tool. My mom had always sent me, being an actress, NAMI stigma busters, essentially there weren't a lot of films that portrayed or did justice or fostered a positive portrayal of people with mental health issues. So, NAMI stigma busters, I can remember she sent me every other month, and a new film would come out and maybe it would be a horror film or somebody would be a mass murderer and have bipolar or whatnot.

So my goal was with this to have it be endorsed by NAMI, so I had people from NAMI watch it and also I've had people who have dealt with bipolar and depression. I've been garnering some—not testimonials. That sounds weird, but just having people watch it. They really appreciate the film. They came to our opening festival, our premier festival out here and had a booth in the lobby. We're playing the film at the national NAMI convention center in December. That's really for me the top, fantastic, definitely a dream come true.

Chilton: That is so awesome.

Frederick: It's really cool.

Chilton: What's great is that you spoke to them prior.

Frederick: Well, yeah. No, I wouldn't have asked for an endorsement from them before the fact, but again, that was what my fingers were really, really crossed for, to have their stamp of approval. There aren't a lot of films in the media that portray mental health in a positive light. I'm so, so happy to be on that roster.

Chilton: I'm so happy you made this film. I love what you did. You portrayed mental illness in a positive light.

Frederick: That was really important, to show that there is light at the end of the tunnel. Otherwise, it's just, it can get dismal.

Chilton: Have you had any negative response from anyone at NAMI about the meds?

Frederick: Not at all. And that was the thing, too, not to get too specific within the film of what meds were being taken, to keep it general. And over the course of seven years, so many different meds have come out. If it erred on the side of anything, it would be a little nonspecific for medication routines. But again, I didn't want to make it too much of a cause film. I felt like that wouldn't allow for people to ingest the message about the strength of facing a mental health issue. When you hit people over the head, nobody wants to hear it. I really tried to make that the underlying, the underflowing river underneath the actual story, which is the family and piecing a family back together.

Chilton: You did a very good job with that. If I didn't know what I was watching, if I turned on Netflix and there it was and I started watching it, it wasn't like men-

tal health hit you in the face. It was about what you said, this woman and her journey at the beginning, that opening scene is so—powerful. It was just like, “Whoa!” It gets you right in. And it went on and yeah, the mental illness was there, but more importantly the human relationships were there first.

Frederick: Great! I really appreciate that. You know what it’s like when it becomes so much, it’s just like foie gras. You’re like, “I can do whatever issue it’s about.” But having that underneath of what everybody’s dealing with was more realistic to actual life. It’s the thing people don’t want to talk about, but it’s there. Thank you for that.

Chilton: Your father helped with the meds in your community?

Frederick: There weren’t many resources for mental health. There was a great doctor, Jerry O’Brian, a psychiatrist, who, along with my father, who was a pharmacist, and my town. I think there were seven people who were in charge, on the board of directors, of the North Iowa Area Transition Center who would go through the process of taking care individually and giving a lot of individual attention to each of the people who were under their care at the transition center.

My father devised a way of keeping track of medications, it was very common for the really mentally ill to forget to take meds with the frequency and the amount that they needed to take. Basically, it was writing down how many, and they would come in and bring their meds in, it still is quite a small team and very admirable, I think, for all of North Iowa to be taken care of and reaching out. The amount of time they’ve put in for helping out the people, the mentally ill, it was really admirable.

Chilton: Your parents sound amazing.

Frederick: They are! They’re really amazing people!

Chilton: And you’re following in their footsteps. You chose well.

Frederick: (laughs) Thank you!

Melinda Chilton: (laughs)

Frederick: They have their moments. I love them, but they do have their moments, but the stuff they did, they gave their lives to. My mom is a psych nursing professor as well. She trained all the nurses in North Iowa, all the psych nurses and was a teacher for 35 years as well. They’re really cool people. That was their passion.

Chilton: How did you get the role.

Frederick: I was looking for something to do. My parents’

friend gave me the script and said he would really like me to do it. He loosely based it on my grandfather and my aunt and asked me if I would have returned home and hung out with my grandpa and basically taken my grandfather out of the nursing home and helped my grandfather to die on his farm instead of dying in a nursing home. It was a really cool story. It was a cool script.

Chilton: It’s a great script.

Frederick: It was a powerful script.

Chilton: The writer, Richard Schinnow, is a friend of your parents?

Frederick: Yes.

Chilton: He nailed that script. That was some strong words he gave you.

Frederick: Yeah. He really did.

Chilton: Who was the director?

Frederick: Ron Vignone. He’s a beautiful woman’s director and he was the editor as well, which was great not only economically, (laughs) but artistically because he knew what shots to get in a limited amount of time. And for casting, you had mentioned Rylie, and I really wanted to cast locally. We auditioned over 400 actors from across the state. I wanted to make sure it was authentic but the other thing is, you move out to LA and you see so many people trying to become actors—actually, in Iowa, when people started coming out and making films—I saw *Twister* being shot in Iowa—And everybody was all excited about these movies and LA coming out and starting to utilize the Iowa landscape. But I remember one of my best friends said, “I got a part in *Twister*. It’s so amazing!” And basically, it was the side of his head, you can see his profile.

Chilton: But that’s exciting!

Frederick: “You’re famous now! You’re an extra in *Twister*!” (laughs)

Chilton: Yeah!

Frederick: So, I wanted to show the talent that we have in Iowa.

Chilton: Oh, she was great. I thought she was a seasoned Hollywood girl.

Frederick: They’re all brilliant actors.

Chilton: Are most of your actors local?

Frederick: They were all Iowans except for Tom Bower. He was—

Chilton: He played your grandpa.

Frederick: He lives in LA, but he had ties. He spent all his summers in Iowa. I made sure they all had an Iowa tie.

Chilton: He was amazing.

Frederick: And Joel West was born in Iowa, but he moved out to LA and was a Calvin Klein underwear model for a while—

Chilton: I could see that.

Frederick: —with Ashley Kutcher. (laughs)

Chilton: He was very pretty.

Frederick: Yeah, he was pretty. (laughs)

Chilton: I'm like, "Do another thing with Junior!" (laughter) It's an extremely well-done film. I see a lot of indie films and a lot of filmmakers. Some films work. Some, back to the drawing board. Your film is brilliant, very well done, and I don't give empty compliments. I really, really mean that. I was very, very impressed. That's why I went in to see who the crew was, the director, the writer. The director was also the editor?

Frederick: Yeah.

Chilton: He told a good story. The editor tells the final story, doesn't he or she?

Frederick: Absolutely.

Chilton: It has their little stamp on there. The editor is the last one to go with it. Bravo to the editor.

Frederick: Thank you so much. And the seven years that he took carving and carving out to see what he had, what was in that, what came out at the end was just—

Chilton: Good analogy. If I understood correctly, he has anxiety disorder?

Frederick: Yeah. Ron deals with anxiety. There's one in five people who—and those are the stats. Some say that one in five people deal with a mental health disorder, some say one in two, some say one in three.

Chilton: You mentioned depression. There's depression and clinical depression. There's anxiety, and there's a spectrum in a lot of this when it comes to mental health. There's less of a spectrum if you have a spinal cord injury and you can't walk. That's quite obvious, you have a mobility issue. It's the way you put the numbers out and what the definition is of the respective condition you're dealing with.

Frederick: Absolutely. That's a really good point. Ron

has dealt with anxiety. I myself have dealt with clinical depression and anxiety. It's hard to talk about that. I'll be right in there with everybody else. I don't know. It's a hard and scary thing to talk about. It's a tough thing.

Chilton: I know. We still have these—whether it's conscious or unconscious bias, it does exist. When it comes to employment, it's a huge issue. Do you disclose or not?

Frederick: Yeah.

Chilton: It's interesting you have a scene in the movie about that, where Kathy is applying for a job at the coffee shop.

Frederick: Oh, right, where she's just so tired of hiding it that it's right up front. You're dealing with stress and clinical depression and bipolar.

Chilton: And the coffee shop owner is like, "OK, let's give it a try." Kathy was honest about her stuff. So was the coffee shop owner. She said, "I'm not sure if this will work." I think she says, "You're hired," and you say, "Are you sure?" and the coffee shop owner says, "No, I'm not sure, but I'll try it." It's just two women being honest with each other.

Frederick: Melinda, that's so funny, because that scene always gets a great laugh of relief from the audience, too, which I never expected. The fact that she just comes out and says it and there's no holds barred, and she says, "You're hired," and then there's the acknowledgment of that and the refreshingness of—that scene, I'm always surprised that there's laughter. Really?

Chilton: And then I loved when Cori comes in and pulls her little stunt and the coffee shop owner comes right back.

Frederick: And she's like, "Oh, yeah! It'd be good if you were nice." "Well, I hired her because she's nice."

Chilton: The writer found so many beautiful moments, and some truths.

Frederick: Thank you so very, very much for saying—for appreciating *Two Ways Home*.

Chilton: I had my own little private screening this way.

Frederick: I'm really happy that you enjoyed it and appreciated it and you weren't bored.

Chilton: No, oh, my God, no. The cast was amazing. That Tom Bower is something else.

Frederick: He really is. He's just an amazing screen actor. ■ ABILITY

A FILM BY RON VIGNONE

TANNA FREDERICK TOM BOWER

TWO WAYS HOME



Embrace the past. Find your future.

A FILM BY RON VIGNONE TANNA FREDERICK TOM BOWER JOEL WEST RYLIE BEHR "TWO WAYS HOME" MUSIC BY KEVIN BROUGH PRODUCTION DESIGNER SONYA NAUMANN
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ORIGINAL SCREENPLAY BY RICHARD SCHINNOW SCREENPLAY BY COURTNEY KIRKPATRICK & EDWARD KIRKPATRICK AND TANNA FREDERICK PRODUCED BY TANNA FREDERICK DIRECTED BY RON VIGNONE

COMING SOON



Peanut Butter Falcon

Actor Zack Gottsagan & Advocate Shelley Gottsagan

An actor with disabilities is born to a disability rights activist. It seems like a far-fetched Hollywood script but in reality, it's 100% true. Meet the Gottsagans—Zack whose breakout role in *Peanut Butter Falcon*, along side Dakota Johnson and Shia LaBeouf, has put him on the map and his mother, Shelley, whose activism for disability rights predates her son. *ABILITY Magazine* was able to chat with Zack and Shelley in between events in an increasingly busy schedule.

Zack is a main actor in *Peanut Butter Falcon*, a role that was written specifically for him. In it he plays, Zak, a young man who lives in a nursing home because his family isn't in the picture and the state has determined he can't live on his own. In his quest to meet his hero, an all-star wrestler, he escapes and takes off into the night. Zack is a man with Down syndrome. The film is authentic to things in his life experience, something we don't see in media often enough. Throughout the conversation, we learned about Zack, but we also learned about his activist mom. Shelley said when doctors told her to leave Zack at an institution because He'd be a vegetable, she told them, "It's a good thing I'm a

vegetarian. I'll take my vegetable to go."

Shelly Rohe: Hi, Zack!

Zack Gottsagen: Hi.

Rohe: I saw your movie, it was great.

Zack Gottsagen: Thank you.

Rohe: I hear that you have been an actor for a long time. Can you tell me a little bit about that?

Zack Gottsagen: Yeah. For me, I was in school before I was in movies. I went to a Palm Beach High School. Dreyfoos School for Arts and of course, Middle School of the Arts.

Shelley Gottsagen: We had to rely on the Office of Civil Rights, because Dreyfoos refused to take any students with disabilities, so we had to get the Office of Civil Rights to let them know that if they didn't comply, that their school was being shut down.

Rohe: Wow.

Shelley Gottsagen: Zack was the first student with Down syndrome to be fully included in the Palm Beach County school district. We spent most of his childhood in court. (laughs)

Rohe: That's so frustrating. Look at what it got you! Now they get to say that they're proud that your son came through the system, but they won't mention that they didn't want him to come through the system.

Shelley Gottsagen: They won't, they know better. He's come out very strongly in local newspapers and said that this was despite the school system, not because of it.

Rohe: Really?!

Shelley Gottsagen: And he talks about how he was mistreated. They would not even answer any questions or try to take claim for his success. They know better. (laughs)

Rohe: That's good.

Shelley Gottsagen: Yeah, they were pretty wicked. There were some good people along the way, but it was a system that had to be fought.

Rohe: And it's still happening now, but back in the day, it was a national issue. Even with IDEA, they're still trying to fight it.

Shelley Gottsagen: There's lots of compliance issues. It's awful. It's still awful. I still struggle.

Rohe: Zack, how many movies have you done?

Zack Gottsagen: Eight movies.

Rohe: Eight? Wow! What was different about this one?

Zack Gottsagen: This one was kind of like more of a business.

Rohe: Business?

Zack Gottsagen: Because it was a feature it was more like a business.

Rohe: I see. What were the other ones like?

Shelley Gottsagen: I don't know if it's OK if I help out a little?

Rohe: Sure.

Shelley Gottsagen: He did many movies with a group called Mountain Farms. It's a group that believes in

inclusion and high-quality movies. They do short independent films, and they gather a group of people, half of them without disabilities, half of them with varying types of disabilities, and they actually write the movie together and they perform it together. They are independent films. There was one movie that was a behind the scenes and that movie won multiple awards, and Zack was the keynote speaker at the 25th anniversary of the Americans with Disabilities Act at the Smithsonian, and they showed that movie. He was able to talk about that whole process. They followed three of the actors with disabilities into their real lives, and Zack was one of the actors they followed. They came and he lived in his own apartment. At the time he was working, so they interviewed his employer and the things that were important in his life. They followed him, and that one was shown all over the world.

Zack Gottsagen: Yeah. I would say it's kind of more learning.

Rohe: How long was your speech, Zack?

Zack Gottsagen: How long was it?

Shelley Gottsagen: Oh, he talked for about 15 minutes or so. And there were advocates from all over the world attending.

Zack Gottsagen: Yeah.

Rohe: What was the most fun thing you did at the Smithsonian?

Zack Gottsagen: Several fun things.

Shelley Gottsagen: They had a lunch counter where the well-known protests took place for the civil rights movement. They were celebrating all types of civil rights, but particularly the part that Zack was involved in was the civil rights of people with disabilities.

Rohe: And that was the 25th anniversary of the ADA?

Zack Gottsagen: Yes.

Shelley Gottsagen: He was the keynote speaker.

Zack Gottsagen: Yeah.

Rohe: So you were asked to be the keynote, which is really great. Have you done other talks around the country on different anniversaries like the ADA or December 3rd, which is the International Day of Disabilities?

Zack Gottsagen: Yes, I have.

Shelley Gottsagen: Zack is doing a lot of things at the Center for Independent Living. It was more local things, not really national.



Dakota Johnson and Zack

Rohe: In Florida?

Shelley Gottsagen: Yeah. He was speaking in Palm Beach County. Zack does a lot of advocacy. He's met with different legislators on different issues, issues around the enforcement of the ADA and also the lack thereof, of enforcement, is what the issues were.

Rohe: When you were in Washington DC, were you able to meet with legislators like Senator Harkin, who drafted the ADA?

Zack Gottsagen: Yes, I did.

Rohe: You did get to meet with him? I think he was just retiring right around that time, which is great if you met him.

Shelley Gottsagen: Yes. There was a big march, and we were able to go to the march, and he was there.

Rohe: Senator Harkin wrote a column for *ABILITY Magazine* for 14 years.

Shelley Gottsagen: Oh, awesome!

Zack Gottsagen: Yeah, cool.

Rohe: Can you give a background of how you got involved in the *Peanut Butter Falcon*, how that came about?

Zack Gottsagen: Tyler and Mike, I met at camp, at Zeno's camp.

Shelley Gottsagen: Through that group, Zeno Mountain

Farms, Tyler, who is one of the writers in movie, was an actor in a movie that Zack was in called *Bulletproof Jackson*, and Mike did some camera work or editing. They got to know Zack over a period of three years and they formed a friendship. Zack told them that he wanted to be the star of a feature movie, and they told him, basically, Hollywood isn't exactly looking for actors with disabilities, and so he told them, I guess that means you guys need to write and direct and I'll have to act in it.

Rohe: (laughs) How long did it take for all of this to come together?

Zack Gottsagen: I'll say five years.

Rohe: That's a good amount of time. Did you give them some ideas? Did you have any ideas about the film?

Zack Gottsagen: For the film, yeah.

Rohe: Can you tell me one thing you thought of?

Zack Gottsagen: I'll say *The Peanut Butter Falcon*.

Shelley Gottsagen: He came up with the name of the film.

Rohe: Oh, did he? Nice!

Shelley Gottsagen: Some of the dialogue in the film was improv that Zack did, like Rule number one: party. That was not in the script. He did that. (laughter) Also, Zack did all his own stunts in the movie.

Zack Gottsagen: Yes.



Zack loves wrestling

Rohe: Wow! You fell out of the window?

Zack Gottsagen: Yup.

Rohe: Wow! What else did you do, did jump off that big platform?

Zack Gottsagen: Yup.

Rohe: Do you like to swim?

Zack Gottsagen: Yes, I do. That's high, 40 feet.

Shelley Gottsagen: They had a stunt double for him, but Zack refused to use the stunt double. Zack, you tell them why you did your own stunts.

Zack Gottsagen: Why? Because for me, on this one film, I wanted to show Tyler and Mike I could do it.

Rohe: What was the wrestling scene like? Was it hard to do?

Zack Gottsagen: Um, no.

Rohe: Was it fun?

Zack Gottsagen: Yeah, it was fun.

Rohe: So Zeno Mountain Farms, you had flown up there and done *Becoming Bulletproof*, you said?

Zack Gottsagen: Yes.

Rohe: How long did it take? Did you film up there?

Zack Gottsagen: LA.

Shelley Gottsagen: Yeah, it was in Venice, California, where they filmed. And they all lived together for a period of time while they wrote and filmed the movie. There were bunk beds and mattresses all over the place, and they all just hung out. Zack would go every year, he would fly out there by himself and hang out with his buds.

Rohe: I thought they were in Vermont?

Shelley Gottsagen: They're out of Vermont, but the movies they would do they would film in LA, like in Venice.

Rohe: We did an article called *The Homecoming*, I wonder if you saw that film?

Shelley Gottsagen: We haven't seen it yet. Zacks in it.

Rohe: Oh, he's in *The Homecoming* as well? How funny!

Shelley Gottsagen: Yes.

Rohe: Then you probably know Eileen Grubba. Do you know her?

Zack Gottsagen: Oh, yeah, actually, I do know her, yes. Yes, I was with her.

Rohe: Should we tell her you said, “Hi”?

Zack Gottsagen: Tell her hi from me.

Rohe: One of the things that I noticed was the language in the movie. Was there a concern about the way language was going to be presented?

Shelley Gottsagen: Are you talking about the use of the R-word?

Rohe: Yes.

Zack Gottsagen: Yeah.

Shelley Gottsagen: That was a big discussion and a lot of input. It was important that Zack’s role be authentic, and unfortunately, that word has been used for him and many others, and we wanted the horror of that to be in the movie.

Rohe: (sighs) Yeah. Do you know Andrea Friedman. She’s the first actress who was on a network show that has Down syndrome.

Shelley Gottsagen: I’ve seen her.

Rohe: She was on the show *Life Goes On*. She was the love interest of Corky, if you remember the show.

Shelley Gottsagen: Yeah, right, right, definitely! Corky himself *Life Goes On* was so important to Zack.

Zack Gottsagen: Right.

Rohe: We have a video with Andrea Friedman about that. It’s very short and very moving, of kids using that word when she was in school.

Shelley Gottsagen: Yeah.

Rohe: Zack, any similar issue with you when you were growing up, that kids were teasing you and using the R-word?

Zack Gottsagen: I don’t know.

Shelley Gottsagen: I remember at the Boys and Girls Club. (laughs) I remember I almost killed somebody over it. (laughs) Yeah. The kid tried to recover real quick and said, Oh, no, no, that’s not what I said. I thought his name was Ricardo. I was like, Yeah, quick thinking, kiddo!

Rohe: That’s a great comeback!

Shelley Gottsagen: I took his shirt collar, I said, “I think you need a staff member to deal with you, because you don’t want to deal with my rage over it!” (laughs)

Rohe: When the kids say that to Andrea, she said, “If you don’t stop, I will tell my sister”, and her sister would take care of them. (laughs)

Shelley Gottsagen: (laughs) Yeah, you know it still happens.

Rohe: The other thing we noticed on language in the movie is that you weren’t using ‘people first’ language. Was that also more indicative to being real, being authentic?

Shelley Gottsagen: What they’re saying is that instead of staying ‘I’m a person with Down syndrome,’ you were saying in the movie, ‘I am a Down syndrome person.’ Do you know why?

Zack Gottsagen: That’s how I played it for the movie.

Shelley Gottsagen: The writers were using it the way Zack said it. They gave me an example of when they were all hanging out one night and Zack kind of disappeared for a while. They didn’t know where he was, I guess he had gone to a bar somewhere. I don’t know where he went. Anyway, when Zack came back, they said, ‘We were worried about you?’ And he said, “Don’t you know? I’m a Down syndrome person. Everybody likes me. I can go anywhere I want and make friends.” (laughs) They were just using the language the way Zack tends to speak.

Rohe: Do you remember, did you go to a bar, Zack? Where did you go?

Zack Gottsagen: I don’t know.

Rohe: You’re not going to say it in front of your mother. (laughs)

Shelley Gottsagen: (laughs)

Zack Gottsagen: (laughs) I don’t know.

Shelley Gottsagen: Do you remember the night when you and Mike were talking about that, when you disappeared?

Zack Gottsagen: Yeah.

Shelley Gottsagen: I think they said he came home with ice cream. I don’t know where he went. But you know where you went. I can step out of the room if you want to tell them. (laughter) But I’d read it! (laughs)

Zack Gottsagen: Look at the credit card statement.

Rohe: Zack, do you know your way around Venice pretty well, then?

Zack Gottsagen: Yeah.

Rohe: What do you do when you're in California? Did you go into the ocean?

Zack Gottsagen: Yeah, yes, I did.

Shelley Gottsagen: Zack has a great sense of direction. By the time he was 11 years old, he was navigating a couple of types of transportation, taking buses and trains. He's really good with figuring things out.

Rohe: Both of your lives have probably changed some since the movie's been released, I would think. As we noticed, the phone is ringing a lot. Has that been the case? Have things changed because of the success of the movie in your lives?

Zack Gottsagen: Yes.

Shelley Gottsagen: What are some changes in your life since the movie?

Zack Gottsagen: Uh, everything.

Shelley Gottsagen: (laughs) Everything, yes! The same people who didn't want to listen to you before are now paying to hear his speech! (laughter)

Rohe: That's good! I know this is a typical question that everybody asks, but can you say some things about working with your two co-actors?

Zack Gottsagen: I would say Shia is a very good person. We have fun and work hard and just do everything that we love to do together. And then Dakota Johnson, she is really good, she too has been fun and she loves working with me, going over the lines and just doing our work putting our show together so people can see our film.

Rohe: Who came up with the secret handshake?

Zack Gottsagen: That was, me and Shia.

Rohe: It's no longer a secret.

Zack Gottsagen: (laughs) Yup.

Shelly Rohe: How about when you were patting each other's cheeks? Was that in the script?

Zack Gottsagen: Yeah.

Rohe: Did you learn lines with Shia, too?

Zack Gottsagen: Yeah.

Rohe: Where did you film this?

Zack Gottsagen: We filmed it at Savannah, Georgia.

Rohe: So, you've done a lot of traveling?

Zack Gottsagen: Yeah. Yes, I have.

Rohe: (laughs) Will you be traveling more for the promotion of the movie?

Zack Gottsagen: Yup.

Shelley Gottsagen: Where's the next trip, Zack?

Zack Gottsagen: England.

Rohe: Oh, very nice. Have you been overseas before?

Zack Gottsagen: Nope. I have not.

Rohe: You'll have a great time. Is this for the movie? Is it a speaking engagement?

Shelley Gottsagen: The London Film Festival.

Rohe: Are you coming out to Los Angeles any time soon?

Zack Gottsagen: I think so, yeah.

Shelly Rohe: Do you know what the event will be?

Zack Gottsagen: I don't know yet.

Shelley Gottsagen: Well, what we think (laughs), we're waiting for the final word, but it looks like Zack may be invited to the Academy for the—

Zack Gottsagen: The governor awards.

Shelley Gottsagen: Oh, yeah, that's right, the governor awards. We're waiting for definite, but we heard yesterday that it looks like he may have a seat at the table.

Rohe: That would be great! What about Media Access? Are they inviting you out?

Shelley Gottsagen: I'm not sure yet. Right now, he's got so many invitations all over the country that I've turned it over to his manager and his agents. It was more than Zack and I can handle.

Rohe: Sure.

Shelley Gottsagen: It was getting overwhelming. I had to retire from my job in order to try to keep up with everything.

Rohe: That's good news-bad news, right?

Zack Gottsagen: I've been off of work for the past five years.

Shelley Gottsagen: Five weeks.



Zack with Michael Schwartz and Tyler Nilson

Zack Gottsagen: I mean five weeks.

Shelley Gottsagen: Zack worked for a theater, and the theater unfortunately closed. He wouldn't have been able to keep up with his work schedule anyway.

Rohe: Are you part of a speaking bureau now?

Zack Gottsagen: Yeah.

Shelley Gottsagen: We're just still kind of balancing, he's going to be the keynote at the National Down Syndrome society in June. He keeps getting so many invitations. He just spoke to 2,000 people up at the Hearst Castle, and Maria Shriver. That was really cool.

Rohe: That is a great venue.

Shelley Gottsagen: He's getting a lot of opportunities, and it's really good. He's being received well.

Rohe: I've heard so many times people talking about the success of the movie, being a pivot point to show the industry that you can be successful. It's a little bit of history being made.

Shelley Gottsagen: Yeah. I mean, really, what's been amazing is some of the reactions, like, we were just at the Angels game, and Albert Pujols, the baseball player, he has a 21-year-old daughter with Down syndrome, and his wife said that after they saw the movie, they pulled their daughter out of her day program and realized she could live an independent life. And we've heard that from other people, that they've made life changes. Zack

was working on a PSA when he was out in LA last week on employment of people with disabilities. One of the other actors was a man with autism, and this man is a young man, and he came over and he gave Zack a superhero cape that he said he would wear to get strength. This young man had recently attempted suicide because things were so difficult in his life, but he said after he saw the movie that he had the strength inside and he can accomplish his goals and dreams, too.

Rohe: Wow, that's nice. So, Zack, that must make you feel pretty good.

Zack Gottsagen: Yeah.

Rohe: Did you ever think anything like this would come about, to where people looked at what you've created in the movie and had that kind of response?

Zack Gottsagen: I would say it's for everybody in the world to see. To inspire the world.

Shelley Gottsagen: When we talked about doing the movie, the goal was to change the world for people with disabilities and to make the world see that everybody has talent, everybody has ability. It's so necessary. I got involved with the disability rights movement back in the 1970s fighting for curb cuts at my college at Penn State.

Rohe: Wow, good for you! I had no idea you had this background. This was before Zack was born, then?

Shelley Gottsagen: Yeah, it was way before Zack was born. In fact, I'm a social worker, but I quit my first job



Zack at a screening of *Peanut Butter Falcon*

because I didn't believe in the institutionalization of people because of disabilities. So, way, way, way back in the '70s, I did a lot of activism on the disability rights movement. I ended up as the director of a center for independent living and worked as the development director for CILs for 18 years. It was just fate that Zack ended up being my kid.

Rohe: I've been thinking about that.

Shelley Gottsagen: It was like, it was just one of those things that's so cool. I was fortunate that I didn't buy into the whole medical establish bullshit. Like, when he was born, they said he'd never walk or talk, he'd be a total vegetable and I had to put him in an institution. This is New York City in 1985.

Rohe: '85?

Shelley Gottsagen: I looked at them and I said, "It's a good thing I'm a vegetarian. I'll take my vegetable to go."

(laughter)

Rohe: Oh, ouch! That's a t-shirt!

Shelley Gottsagen: I was fortunate that I have a strong

civil rights background, too. I did anti-Klan work for years, so I could stand up. We did one of the very first ADA suits after the ADA passed against Little League for refusing to allow kids with disabilities to play.

We asked that every coach in the system, every coach throughout the U.S., be trained to include kids with all disabilities. The ACLU took the case on Zack's behalf.

Rohe: So, Zack, you've been quite familiar, then, with your mother's antics?

Zack Gottsagen: Uh, yes, I have.

Shelley Gottsagen: (laughs) Zack has always been an excellent advocate. When he was in school, he conducted his own IEP meetings.

Rohe: Oh, my gosh!

Shelley Gottsagen: By the time he was in middle school, and Zack was a better advocate than I am because he's very diplomat. I get angry. He gets quiet and he stands up and folds his arms and says, "I'll wait for you-all to be quiet, and then we can proceed and move forward." They had started a program when he was getting out of high school. They selected eight students with intellectual or developmental disabilities,

whatever, to go to this college thing. He was one of the eight students who were picked. He started it, and then he called a meeting. I had no idea what he was going to do. He said, “You know what? This program, I’m auditing classes, but other people go to college and get degrees. You’re not giving me a degree. You’re having me work in the cafeteria saying you’re giving me work experience, but other people work, and when they work, they get paid.” He said, “I just can’t get the difference between your program and slave labor.” (laughter) I was flabbergasted. He said, “I’ve studied fascism, and this really resembles it.” (laughs) I was happy he had gotten into this program, but he said, “I want to let everybody know, Mom and everybody else, I’m outta here. This is not the way people should be treated.”

Rohe: Wow!

Shelley Gottsagen: He’s a remarkable advocate.

Rohe: Any comments on that Zack?

Zack Gottsagen: No. (laughter)

Shelley Gottsagen: He’s been really great at standing up, not only for his rights, but he would go in front of the county commission and give them hell on para-transit and how they pull up and expect people who use wheelchairs to get down and there’s no curb cut there. Or he would talk about issues around people with autism, with any type of disability. He was very articulate and able to confront the county commissioners or legislators on their bullshit.

Rohe: Yeah, getting off a bus and there’s no curb cuts, there’s always an area of disconnect that, “It’s not my job, that’s city planning.” It’s amazing how people disconnect and don’t want to take on having common sense on certain things.

Shelley Gottsagen: Yes, yes. Remember when you were talking to them about that, in front of the county commission?

Zack Gottsagen: Yeah.

Shelley Gottsagen: Yeah, you were pretty young when you were doing that, too.

Rohe: So, he was working for people with mobility issues? Zack, you’re not using a wheelchair, right?

Zack Gottsagen: No.

Shelley Gottsagen: Never. But he had friends who did.

Zack Gottsagen: Yeah.

Shelley Gottsagen: Also, when I was fighting to get

Zack into that School of the Arts, we were fighting on behalf of several kids with disabilities. The one who still kills my heart because I didn’t win this one was a kid with autism who was a filmmaker, so talented. And they said when he went in front of the judges, he didn’t make eye contact. And I’m like, “He makes perfect eye contact with the camera. What else do you want?”

Can I tell one more Zack story?

Rohe: Sure.

Shelley Gottsagen: When Zack was in fifth grade, he was on safety patrol. Everybody on safety patrol gets to go to Washington DC. But they said Zack couldn’t go, because they won’t take a student with a disability. So, we filed with the Office for Civil Rights, and of course they ruled that Zack has to go. He has the same rights as anybody else. So, when we showed up that morning, they said that because he has a disability, he has to use a wheelchair.

Rohe: What?!

Shelley Gottsagen: Well, I was about ready to wring somebody’s neck. And Zack, very calmly back then, luggage didn’t have wheels on it, and very calmly Zack said, “Mom, I’ll handle it.” Here he was in fifth grade, and he said, “Anybody who wants to be in my group, we can put all our luggage on the wheelchair. We can just push it and get around faster!” (laughter) He’s always been able to think out of the box. He says, “It doesn’t pay to get mad. Just figure out a better way to do it.” He’s taught me. He’s been my teacher in terms of advocacy. He does it with such flair. (laughs)

Zack Gottsagen: I love you, Mom!

Shelley Gottsagen: I love you, too, kiddo! ■ ABILITY

Quincy Jones Exceptional Advocacy Award Recipient
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DARUMA

A Film Wish Coming True

Name one indie movie you've seen lately. Would you be able to name an actor in an indie movie? What exactly is an indie movie and why do we care? Great question, I'm glad you asked. An indie, or independent film, is thought of as a film that is produced outside the major film studio system, in addition to being produced and distributed by independent entertainment companies. And there are a lot of them made each year. If the Sundance film festival is snapshot of the top independent films released each year, then the 4,000+ submissions they receive is just the tip of the iceberg.

Just because they are called indies, does not mean they have no budget or are poorly made. Sure movie-making budgets span a large curve starting with low-budget around \$200,000 to big-budget studio films over \$100 million. Most independent films cost about the same as major studio films. It is all the other things that go into this collaborative art form that make a film an independent film. From the writer to producers/directors to actors, most of the people are relatively unknown.

It's no secret that the writers at *ABILITY Magazine* have an interest in actors, writers, and film makers. There are 30 years of stories in which we've spoken to many well-known people. We have been frustrated by the lack of actors with authentic disabilities in roles on TV or film.

We recently spoke with crew and cast of the yet-to-be-shot indie film, *Daruma*. You read that right; it hasn't been filmed yet. This film has all the hallmarks of an

independent film; little known (for now) writer, actors, and an up-and-coming director. It is not being done by a major studio, but there is something this production is doing that sets it apart from all the others, they are casting people with authentic disabilities and hiring crew people with disabilities.

Daruma is inspired by a true story and is about two unlikely friends: a paraplegic and a double amputee. Tobias Forrest and John Lawson star in this film directed by Alexander Yellen. In this story, the two main characters must work together, even though they don't like each other, to transport the four-year-old daughter one man didn't know he had, to her grandparents across the country. In this expose, which spans two issues, we'll delve into each of their journeys which, when layered on to this project, bring true richness of life experience to *Daruma*.

Kelli McNeil is the writer of *Daruma*. Even though she started out as a theater major at USC (University of Southern California), and has experience in PR and marketing, she ultimately became a writer, currently represented by Gersh. The name *Daruma* started with a painting and Japanese proverb in which the *Daruma*, founder of Buddhism, councils his pupil Eka. "I remember hearing the fact that he's [her brother] now in a room with a young man who has no arms and he had just lost the use of his legs and I flashed to this painting of the *Daruma*," says McNeil. In researching this project; she came across the *Daruma* doll. Legend





says when you make a wish, you color in one eye of the Daruma doll, when the wish comes true, you color in the other eye. “In the script, John’s character has a Daruma tattoo on his back, and one eye is colored in. At some point during the journey, Toby asks him, ‘What did you wish for?’ You find out that what John’s character had wished for was forgiveness. That truly is the crux of the story, it’s about learning how to forgive yourself.”

The project started for McNeil over a decade ago when her brother had a spinal cord injury. She is quick to point out that *Daruma* is not about him, it is inspired by him. The characters in the film may be fictionalized, but the memories are vivid. “When he was recovering in a facility in Houston, the spinal cord injury ward was full, so he was moved into a room with another young man who had lost both of his arms in an electrical accident. Both of them had just turned 21. They kept getting in trouble from the hospital staff because they kept sneaking out. I was ultimately struck with the way people look at disability. It doesn’t define him. It’s not who he is. They were these normal kids coming into adulthood trying to figure out who they were.”

Together with the director of the project, Alexander Yellen, a proof-of-concept video was shot. A proof-of-concept is typically a scene from the script. It can show what the writer, director, and actors can do as well as provide a film’s viability on the big screen. The proof-concept is typically used to show to studios and financial backers to get their investment in a film. So, to start, McNeil and Yellen began with casting the main characters. They were able to find Tobias (Toby) Forrest and John Lawson through their initial casting notice. Since

then, they have been working on the full-length feature.

“The script has been through several iterations since we shot the proof-of-concept, and as we’ve done table reads, I’ve modified the script. As a writer who does not have a disability, I’ve modified the characters based on Toby and John because of what they can do. As we’ve gone through the process of working to get traditional funding for this, traditional financing, we’ve had a lot of interest and we’ve come very close with a lot of production companies, but ultimately the idea of casting authentically has been a barrier that nobody wants to cross,” states McNeil.

She continues, “Because there are movies like *Peanut Butter Falcon* that have been released and they’re doing so well, obviously the dialogue has started and change is happening. But I feel that there’s a risk that people aren’t necessarily willing to take. We’re doing a very scaled-down version of the budget we think that we can accomplish through crowdfunding and putting our own resources, our own money, towards it. I think that this is an opportunity to change things, I really do.”

This production has gotten creative with financing through Seed & Spark, a crowdfunding website. The campaign will end on November 30, 2019 and they hope to have the film shot, edited, and ready to be shown by October 2020. They also plan to employ people with disabilities behind the camera and will have a link on their crowdfunding page to apply.

Here is our interview with Alexander Yellen.

ALEXANDER YELLEN INTERVIEW

Alexander Yellen is a cinematographer and director in Hollywood. He has worked on feature films, television shows, and has won awards for his work in the industry. He is currently working on a project that he shot a concept of, *Daruma*. The two main characters in this film happen to have disabilities. It was important to Yellen, and others working on this project, that the actors portraying these characters have the authentic disabilities themselves. The decision not to have ‘name’ actors in the film is resulting in an all too common theme—the money people don’t want to take the risk. So how does a film like *Daruma* get made? Finding the money has taken a creative twist. *ABILITY Magazine* caught up with Yellen and discussed Africa, *Daruma*, and what Hollywood needs to know about hiring actors with disabilities.

Shelly Rohe: Tell me a little about growing up.

Yellen: I had in some ways a very normal childhood and in other ways a very abnormal childhood. I grew up in Washington DC, but my parents are paleoanthropologists. They study human prehistory. I spent time with them on excavations in southern and eastern Africa.

Rohe: Nice! I was going to ask where.

Yellen: When I was very, very young it was South African Botswana, and later we spent a number of summers in the Congo. It was Zaire at the time, and now it’s the Democratic Republic of Congo.

Rohe: How long would you be there for?

Alexander Yellen: I think it was about seven or eight weeks at a time. I lived in Botswana as a small child for about a year. Have you ever seen a film called *The Gods Must Be Crazy*?

Rohe: Yes, I have.

Yellen: The Khoisan, the bushmen who find the bottle?

Rohe: Right.

Yellen: We lived in the Kalahari Desert with the Khoisan.

Rohe: Wow! What was that like for you?

Yellen: I was very young, so I have limited memories of that particular experience. The first thing is, when you’re a kid, you think whatever your experience is is normal. You don’t process that you’re having an unusual experience for children more broadly. So, it was like, “OK, sure, we’re going back to Africa.” “OK, sure, here

are people who have cultural differences and with whom I don’t share a language, but they’re kids. They like to play. Awesome. I’ll play with them.”

Going back as an adult, there was nothing particularly shocking or surprising. The only thing that threw me a little bit was, in Khoisan culture, there really isn’t a concept of personal space. We went out to do some work during the day, and the first day when I came back, there were four people sitting in my tent, just because that’s the spot with the best shade. It was like a nice spot to hang out. “You’ve set up communal space for everybody.” That’s how it works. It’s not like first-come, first-serve on sleeping space. They acknowledge that that’s where I sleep. That was the only thing culturally that threw me.

Rohe: After childhood, tell me about school.

Yellen: I went to private school in Washington DC from pre-K all the way through high school. DC public schools are historically not great and were particularly not great in the 1980s. My parents were fairly committed to my sister and myself having a good education. They never pulled me out of school to go to digs with them. There were stretches where I lived with other family members or stayed in a dormitory. But I went to a great school and got a fantastic education and also developed a love of photography. And I have to thank my mother largely for that. I played with her cameras. She has been an amateur photographer her whole life. I can remember playing with her cameras at a fairly early age. She got me my own when I was 13, and I don’t think I put the thing down for the next five years.

Rohe: Do you have a favorite picture?

Yellen: A favorite picture that I’ve ever taken?

Rohe: Yes.

Yellen: No, is the short answer, but I have a collection of special images that are particularly meaningful to me. There’s a picture of my father that I took in Botswana. He’s standing on the porch of a platform fence staring out along the delta that I particularly love. Do you know what a Polaroid transfer is?

Rohe: No.

Yellen: Do you remember old-school Polaroids, not the kind that come out as a square, but the kind where you have to peel two pieces of paper apart?

Rohe: Yes, I do.



John Lawson and Tobias (Toby) Forrest in *Daruma* trailer

Yellen: If you take the side that has the wet chemicals on it and you press that side down on a piece of paper, you get a secondary copy of the same image on whatever medium, but it has to be at least a slightly absorbent medium. I did a Polaroid transfer of the flags at the Washington Monument when I was in high school, and it ripped a little bit as it came up, so it has this, very weathered, damaged texture to it that ends up imbuing the image with a secondary meaning that I think is ever more relevant as you look at it, like the frayed fabric of national political life.

Rohe: That sounds hauntingly beautiful.

Yellen: Those are two that jump to mind. And I'd say the picture I took of proposing to Kelli (Kelli McNeil is the writer of *Daruma*) is one that'll rank as an all-timer.

Rohe: Tell me about that one.

Yellen: I had been planning for some time, I had always imagined getting a great proposal picture with Kelli that looks like, "How did you execute that?" I know some people have had friends take pictures, but one, there was no way I could think to do that that wouldn't be creepy—

Rohe: (laughs) Right!

Yellen: —and two, I tend to be fairly particular about photography, and rarely do I trust anybody else to take a picture that I really want to take. I proposed to Kelli in Hawaii, and I had gotten a miniature tripod the week before the trip. She asked, "What is that for?" I said,

"I'm going to up our selfie game." She said, "You don't take selfies." I said, "Yeah, I know. I hand my camera to other people and I'm always disappointed, so I'm going to do it myself and do it right." So, I spent three days looking for the right spot and the right opportunity to propose. It was the story of three days of missed opportunities. Either there would be too many people or the vibe in the atmosphere was wrong or the weather wasn't right. But I'd still set up this tripod with my camera on it and we'd take some self-portraits everywhere, so she got fairly desensitized to the operation. On the third day, we found a beach at the very western end of the island that was deserted, the sun was going down, the light was absolutely gorgeous. I set the thing up on a timer. It was taking one picture every second. I walked her out into just the right spot, walked out next to her and we stood there. It had been a normal routine of self-portraits that she had gotten used to at that point. So, when I went down on my knee to propose, she was completely stunned, totally, totally surprised. It's this picture against this absolutely stunning backdrop of beach and ocean with glowing orange light.

Rohe: Wow!

Yellen: And I have this very sweet, hopeful look on my face with a ring and her hand brought to her mouth in total surprise. It's one of those things that you couldn't hope to execute much better.

Rohe: That sounds amazing! Congratulations!

Yellen: Thank you. She probably told you we just got married.

Rohe: She did.

Yellen: So, you were asking me about school. I got a good education. I developed a love of photography. I went to Wesleyan University in Connecticut thinking about a career in photography. I wanted to be a *National Geographic* photographer. That was my passion, my dream job when I was in high school. The photography department at Wesleyan and I just didn't click. But I started taking some film classes, and that really clicked with me. It turns out that there is not an enormous—or I should say, it turns out that many of the skills from still photography translate well to cinematography. I shot a couple of guys' thesis films. One of my best friends lived in LA and offered to let me stay with him while I got things sorted out, figure out if LA was a place I could live. I tried to make some inroads, but I didn't have any clue what I was doing when I moved to LA. I didn't know anybody, at least anybody in the industry. I didn't have a jumping-off point. I started from scratch and found my way.

Rohe: When you were moving to LA, did you have other jobs you did?

Yellen: Initially—during college I had a summer job selling knives. I was a Cutco knife seller for a couple of summers, which is a thing a lot of college kids did. I think they still do.

Rohe: Yup, I think they do.

Yellen: I had saved up some money from doing that, and even though it gave my father deep anxiety—my father has had a government job his whole life. He's had security and job stability, so the idea of a free-lance art job was absolutely terrifying to him. But my parents were both fairly supportive of my career choice. They said, "If it all goes south, you can always come home. We'll make sure you can get home, so don't worry about that."

Rohe: That's a great thing, that support.

Yellen: And things like, "We'll make sure—you'll have health insurance. Don't worry about that." They were supportive. But no, I never had another job. I didn't do the waiting tables thing or take on a side hustle to make ends meet while I was trying to get a film career going. I got my first paid gig about two months after I moved to LA. I spent a lot of time doing student films. The American Film Institute and USC have renowned film schools, and their alumni want to do bigger and better things. Once you develop a reputation for being somebody who's a hard worker, who shows up, shows up on time, has a good attitude, and maybe even has a decent skill set, people will recommend you to their friends. It really is a network-based business.

Rohe: You've told me a little about how you started in the industry. Can you talk about what you've done?

Yellen: Are you asking how I moved forward in the industry or the work that I've done?

Rohe: Both?

Yellen: From the get-go, my goal was to be a cinematographer. Again, I love cameras, I have always loved the visual storytelling aspect, the power of the image to tell a story. I gravitated towards the camera department right from the get-go doing all these student films. Once people realized I had an aptitude for camera work, especially the ability to pull focus, which is a very niche skill set and one that's in demand, those were the jobs I was offered. I spent some time also in other departments. I tried to work in just about every department, just to understand how they all worked, which would let me do pretty much any job better. I still very much believe that anybody who works in this business should spend time in every department, so they understand all the components that go into making a movie.

Rohe: I do, too.

Yellen: Camera was my first and favorite home. I worked my way up as a first assistant, starting on short films and music videos and growing into the independent feature world. I got into the union that way and was building that career, still with the goal of ultimately becoming a cinematographer, and to further that end, any opportunity to create images of my own. Whether that was working with other friends from various sets who were aspiring in other areas, aspiring directors, actors, editors, assistant directors, producers, all these creative people getting together and combining their talents to create content they were passionate about on the weekend. People are fairly supportive of that kind of thing, especially when you're not undercutting them or competing. And then I would offer to go do second-unit work on some of these features I was assisting on for the credit. I wanted to start building up a list of credits. Some of the B-rolls that they couldn't get, establishing shots, cityscapes, sunsets, driving shots, stuff like that, I would go do for the credit. I built up a reel that way. I had a couple of projects that earned some notoriety, most notably the film *Quinceañera*, which was a Sundance winner I believe in 2006 or 2007. That gave me a degree of credibility. So, when an assistant director I'd worked with said, "Hey, a buddy of mine is directing a movie. It's a low-budget sci-fi film. I think you guys might get along," I had a reel and a résumé and enough credibility that the company, which turned out to be The Asylum, took me seriously and ended up giving me the job. And now they're a famous or infamous company, depending on how you look at them.

Rohe: (laughs) I know of them.

Yellen: They're now most famous for the Sharknado movies. At the time, they did a lot of straight-to-video horror movies and mockbusters, movies that have titles

that sound like blockbuster films but are just a little bit different. My DP (Director of Photography) career really took off with them. That was in a lot of ways film school on wheels for me. They required certain things to meet their delivery standards, but beyond that, they really gave me a lot of space and freedom to experiment and to create looks for films and to take some risks. The great benefit of that was learning what doesn't work—when you can do that on a smaller budget, lower-scale productions, then when you get to bigger-budget things, you really understand what works and what doesn't and also how to create and intuit your way out of a corner. So when something doesn't show up, or you wind up with different weather than you were hoping for, or the set doesn't look like you want it to, or isn't as big, you already have a huge tool kit of fixes for all the problems that you're likely to encounter on a small set.

Rohe: Tell me of one you now have in your toolbox.

Yellen: I think the thing I probably encounter most frequently is just not having the set, as it were, not having a location that reflects what's in the script. You're supposed to be on an aircraft carrier and what you have is a parking lot by a beach. How do you make the one look like the other? A lot of that comes down to your field of view. The audience doesn't know what's outside the frame of the image. There was a famous behind-the-scenes documentary about *Seinfeld*, where they showed the apartment building that Jerry Seinfeld's apartment is in. They said, "If you've ever wondered why this is the only shot we ever have of this building, here's why." And they panned the camera to the left, and it's this obvious LA tableau, with all the trees. For years and years, all you ever saw was this building, and your mind says it's in New York.

Rohe: I used to live in New York, and people would ask me all the time where the Jerry Seinfeld building was.

Yellen: Absolutely. And the answer is, "It's in Los Angeles."

Rohe: Exactly. They didn't want to hear that.

Yellen: So it was, in the case of the aircraft carrier, it was getting a gray piece of foam, like a movie flat, like a 4x8 piece of foam, painting it military gray and moving it around so it feels like different bulkheads on this aircraft carrier and then having a \$20 party fogger so there's smoke moving through the background and shooting out towards the water.

Rohe: Wow!

Yellen: So, you can see the ocean in the distance, your mind says, "OK, we're on the water." You see this wall that says, "This is the right color for an aircraft carrier," and you see the smoke coming through which is something you imagine from seeing catapults. And with the

right sound design, you can create a fairly convincing illusion.

Rohe: Suspension of disbelief. Tell me about where you're at and what you're doing right now.

Yellen: As I spent time building a cinematography career, that created opportunities to direct. I worked for a number of inexperienced directors, so I was sort of a major support element for them to learn and feel comfortable and be successful. And people around you notice that when you're helping directors out. They say, "Maybe this person would be a good director." First, I got two features, one was a werewolf movie and the second one was a haunted house movie, both for TV. And then through the zombie series that I spent five years as the DP of, I got some additional opportunities to direct episodes for television. I built a fairly strong reputation as a director, in addition to being a cinematographer. But by far the bulk of my work has been in genre—horror, science fiction, disaster films, Westerns, and war movies. I haven't done a ton of rom-coms (Romantic Comedies), or a ton of certain melodramatic pieces. One of the fun things about genre is that you can craft subversive messages. You can have a moral or a point, but it's sort of buried under the mask of mindless entertainment. I've always wanted to tell stories that are meaningful and that are meaningful to me and hopefully say something about what's important to me in the world to a broader audience. There are some other projects that I've played around with, but when Kelli showed me the script for *Daruma*, which by the way was the first piece of her writing that she let me see, other than her kids book, within two pages I was laughing. She came in from the other room and said, "Why are you laughing? Is it bad?" I said, "No, it's funny." She said, "Funny bad?" I said, "No, it's funny!" It's these two cantankerous characters who are—it reads like grumpy old men yelling at each other, and it was really funny. I connected with the characters right away. I saw the potential in the story. It said something important to me. It evoked in a lot of ways things that I want to say, that I care about for the rest of the world.

Rohe: Wow.

Yellen: That was three years ago now that she showed that to me, no, two and a half. I said, "The story and the logistics of this aren't especially complicated. We could make this movie." And she said, "OK, but we have to cast authentically. We have to cast actors with disabilities." My first reaction was, "Wow, that's really powerful. Do you have any idea what's out there?" She said, "No. But we have to do it anyway. I have to believe that there are talented actors with these conditions in the world. We just have to find them." I said, "OK. Let's see what's out there."

Over the next year we built up a game plan. We reached out initially to a number of our contacts. We have different



Toby Forrester filmed by Alexander Yellen

overlapping Venn diagrams of contacts in our networks. The reaction we got was generally, “Wow, that’s a great story, that’s a great idea! What names are you casting in these roles?” “We’re casting actors with disabilities.” “Wait, what? That sounds noble. I don’t think it’s going to be a good fit for us.” Our next step was, “OK, if people don’t believe us, we’ll show them.” We went out and did a casting session and found two fantastic actors, Toby Forrester and John Lawson. Interestingly, the character Toby is playing had been written for somebody with a less severe spinal cord injury. It was written as a strictly paraplegic role, and Toby’s a quad. Once we saw him read, the initial conversation was, “I mean, he’s not exactly what’s written, but God is he good! He killed it! He crushed the audition! How hard would it be to change some of the action in the script to make it work for Toby?” And also to shoot other things differently because Toby takes more time to do than a paraplegic person would take, like getting in and out of bed. But you can get around that with editing. You don’t need to physically show him getting in and out of bed every time. That’s an easy change for the script.

Kelli did a pass on the script just for Toby once we had him, because it’s worth it. When you start thinking about disability, this whole process has been extremely educational and eye-opening for me in terms of how to think about disability and actors with disability and writing for them. The thing you realize is that the story doesn’t have to change at all. The things that you’re adapting are so minor and so relatively—like, those actions in and of themselves are so unimportant that this person can live this experience you’re describing in

your script, and the actions are completely adaptable. There’s nothing so sacrosanct that you can’t make it work for somebody regardless of their ability.

Rohe: You were saying when you were growing up that you weren’t really aware of the differences in people. It was just all what your experience was. We want to do that with disability.

Yellen: Absolutely.

Rohe: Actors with disabilities can play anything. They don’t need a role specifically written for them. Do you see Hollywood changing at all?

Yellen: I hope so. I mean, I do. It’s changing already. Hollywood is making progress. Granted it’s in fits and starts, particularly on racial and gender fronts. But disability is still a thing that’s so poorly understood because the issues are not quite so front-and-center in the public discourse. Race in particular is front-and-center every day in public discourse. There are stories about how race affects people’s lives and racial unfairness, racial disparity. Same thing with gender. Gender inequality is something that is in the news every day. But disability isn’t, and mental illness isn’t. There is an awareness gap, and that is also reflected in how people think about representation of people with disabilities in mainstream media. But in a lot of ways that’s a self-fulfilling prophecy: because you see fewer people with disabilities in mainstream media, it’s an issue that is last in minds people who consume that media.



Rohe: We apply symbolic annihilation, that's when you don't see a certain group of people in media. They're not represented, so that population feels that they don't matter. It's called symbolic annihilation. It's been used in the past more for race and gender equality, but it can be equated to disability as well.

Yellen: Sure. So, I'm describing something that you have a name for. I've heard the argument, "Well, so we're telling a story about a character with a disability, but it also has to include time when they were able-bodied, telling about how they became disabled." The first thing I think about it, if they can put Chris Evans' face on a short, skinny kid from South America, why can't they do the same thing with somebody in a wheelchair? Granted, that's not cheap. That's not something that's practical on the lowest-budget films. But certainly, if you're telling a story about a person who represents a person with a disability, technology isn't the barrier to casting authentically. It's a political choice.

Rohe: Do you think there are enough actors with disabilities in Hollywood to cast authentically?

Yellen: I guess the short answer to that is, no, I don't. Are there enough people with disabilities that have the talent to do it? I think the answer is yes. There isn't enough demand for those people to attract people with that talent to try acting. I think that there is a group of talented people to serve the needs of Hollywood when it comes to authentic representation. I just think a lot of those people aren't working as actors right now because they can't get the work. They don't know that it's an opportunity.

Rohe: Kind of a catch-22.

Yellen: Exactly. That's what I was looking for. And again, that's very much the point that Kelli and I are trying to make, and that's why this is meaningful to me on a deeper level.

Rohe: October is the kick-off month for raising funds for *Daruma*. Tell me about that.

Yellen: Initially, I was optimistic about the traditional financing. I thought our proof-of-concept was strong, we had half a million dollars which was the goal at that time. I expected a better outcome. I was initially fairly resistant to crowdfunding, but I also confess that I did not understand crowdfunding well at that time. It felt like I was just going to be hitting up friends and family to give me money, which I don't think anybody would be anxious to do. I wasn't for it. I'm not sure what your experience with Seed & Spark is.

Rohe: I'm wasn't aware of them.

Yellen: I wasn't either. I had never heard of them. Kelli had met the founder at a Women in Film event, Emily Best. She said there was an informational seminar that Kelli couldn't go to but would I go and take notes. It was a really interesting experience. One of the first things that they tell you is not to friend-fund. You shouldn't look at crowdfunding as friend-funding because that's not what your goal is. You don't want to raise money because people feel sorry for you. You need to be building an audience that is genuinely interested in the story you're trying to tell before you tell

that story. One, because those are people who want the product that you're selling. Two, because they're willing to give you money because they believe in it, not because they pity you or they feel like they owe it to you personally. And three, because they're people who will consume your product once it comes out. That's information you can use to demonstrate the viability of the idea and the demand for it in the marketplace to distributors.

Once I had that mindset adjustment, suddenly crowd-funding seemed like a great idea and I was all for it.

Rohe: So, you shot a proof-of-concept, correct?

Yellen: Yeah, we've done a proof-of-concept, and we have a pitch video. We're launching our campaign on October 1. Kelli, in particular, and myself under her tutelage, have been doing a promotional push ahead of the campaign launch. Kelli has a background in marketing and PR in addition to being a talented writer and actress. She is a quadruple threat. She's been incredibly effective at getting sponsorships and partnerships from places like the Reeve Foundation, Media Access, and RespectAbility and helping us make additional inroads in the disability community as well as spearheading our PR push through social media. My strength, one, is in the creative aspects and the physical production aspects, and two, in one-on-one salesmanship. This is something that means something to me, and because I believe that it's important and that this is an honest-to-God way to do good in the world, using the skill set that I have, that it's something that has to be done. This is something that is going to get done, whether we raise our full budget through Seed & Spark or we beg, borrow, and steal and find another way, we're going to make this movie. It is going to happen. Hopefully other movies will follow. We saw *The Peanut Butter Falcon* last weekend, have you seen it?

Rohe: Yes.

Yellen: I think there's a lot of similarities between what they have done and what we are planning to do. There are obviously differences, but we are fortunate to have that film and the good press and good social energy that comes off of that going into doing what we're doing. Because they did a thing that nobody believed in, and it's good.

Rohe: Good! I'm looking forward to seeing *Daruma*, too. Can you talk briefly about the story line?

Yellen: Sure. *Daruma* follows Patrick, who is a down-on-his luck guy with paraplegia living in a disabled vet community who finds out he has a daughter from a one-night stand he never knew about. He's being given custody because the mother had died. Initially he takes his daughter on to get an insurance payout. That tells you something about the kind of guy Patrick is. He learns

fairly quickly that he is not able to take care of this child, so he enlists his neighbor Robert, who's a double hand amputee and with whom he has a particularly can-tankerous relationship, to help him drive this little girl across the country to live with her grandparents. Suffice it to say, hijinks and chaos ensue. It is a road of twists and turns, and really, at the end of the day, it becomes a story about forgiveness.

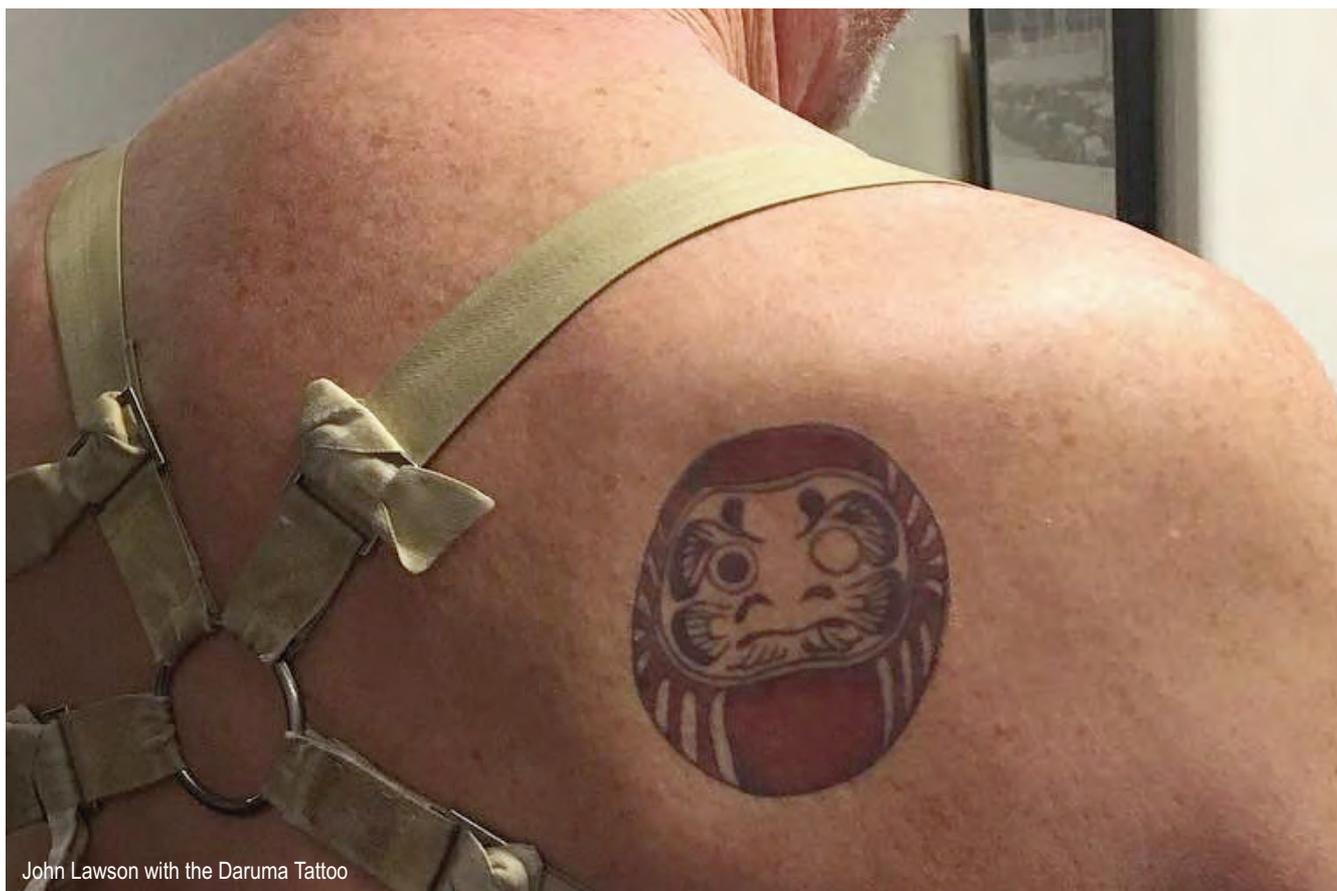
Rohe: You said you had some eye-opening moments. Where any of them related to how you directed? What kind of things would you tell other directors?

Yellen: I had eye-opening moments in regard to how I think about disability. I haven't had tremendous exposure to people with disabilities in my life generally. I have a second cousin who's deaf, and I've worked with some actors with disabilities in generally small roles. I did a Lifetime movie with Marlee Matlin, which is the most substantial project I've done with an actor with a disability, but certainly the depth of my exposure, the depth of my experience with people with disabilities was very limited. Number one, being educated and impressed by the creative systems that people with disabilities have come up with just to participate and function in everyday ways, the ingenuity and the passion and how they don't look at their disabilities as disabilities. It's just a word for a lot of them. And that their daily lives are their daily lives. They don't think about it way I think about it. That was incredibly eye-opening.

For directors in general, number one, just treat them like anybody else. Certainly, be respectful, but don't dance around disability like it's a thing that you have to be afraid of or that it's an elephant in the room. They know who they are. They know what their situations are. They are comfortable with who they are. It's only awkward if you make it awkward. That's the first thing I would say. John's a double amputee, Toby is a quadriplegic, so how they interact physically, like helping Toby transfer from his chair into a car, for example, let him take the lead and be there to support. In terms of giving direction, that's my job. I know how to do that. I treat them as I would any other actor. When it comes to things that are in their specific experience, let them take the lead and just go with it. I think those are probably the two best pieces of advice I would give to other directors working with people with disabilities.

Rohe: Did you have any fears or concerns working with people with disabilities at first?

Yellen: My initial concern was, because I didn't know what was out there in terms of talent, my big fear was finding people who have the acting ability to handle these characters. Because the characters in *Daruma* are deep, rich, nuanced characters—they're challenging for any actor. I'm excited that these guys get to do these roles, and I know they're excited to do them, because they never get to see parts like this.



John Lawson with the Daruma Tattoo

When you see actors with disabilities in lead roles, nine times out of 10 it's a short film, so you don't get the time and the distance to explore the full range of what a character's experience is and on the few major projects where you do, I only know one or two actors who do that, and it's not somebody who has the conditions we're looking for. How many double-arm amputees are there, and how good will they be? I had no idea. Just finding people was the biggest fear for me. And that fear has been assuaged. If you can find people who can do the roles, then we can do anything.

Rohe: Give me a timeline for your goal to end product.

Yellen: Our ideal scenario, we start fundraising in October and ending November 30th. We do soft pre-production before the end of the year with an eye towards shooting in the spring. It's not a winter movie, and a lot of it is more daytime than nighttime, so having at least an equinox or later time, so starting from mid-March—sometimes between mid-March and mid-May going into physical production. And basically having a festival-ready product by late summer, so that the film is going to festivals in August and September of next year, or at least we're doing submissions at that point, so that it can be released in a little over a year from now.

Rohe: That's an ambitious timeline!

Yellen: It is, but it's also not. One thing I've learned

from doing all these low-budget films and all this genre stuff is that you can turn a project around pretty quickly. I don't want to be rushed. I think there will be a lot of very subtle differences in the performance this could take, and I want to make sure we have time to devote to making this film as good as it can possibly be in the edit. That said, having two or three months to do post on a film, this film shouldn't require a tremendous amount of visual effects, so the finishing shouldn't take forever. We're hoping to on-board some of the creative, like composing and sound design, fairly early so that those people can be working with us even during production to generate the base pool of assets that we can then acquire a little more efficiently towards the end of post.

Rohe: It sounds like a really good idea and plan.

Yellen: I guarantee there's something we haven't thought of. We'll learn what that is at, I'm sure, the most inopportune time. Sometimes that's where the magic is. ■ ABILITY

We, at *ABILITY Magazine*, have colored in one eye of our Daruma doll, wishing for the success of this film. We can't wait to color in the other.

To support *Daruma*, go to:
darumamovie.com

In the next issue we interview our friends Toby Forrest and John Lawson



Alexander Yellen Toby Forrest, John Lawson and crew of *Daruma* trailer



"Keep those leg muscles strong and moving," physical therapist Kevin Linde tells John Williams.

John Williams

Fighting Back Against Parkinson's Disease

Recently a friend and I were discussing politics. He supported the present administration's Immigration policies; and I don't. Every time he made a point, I countered with what I believe was a more valid point. He became so angry that he said, 'Go to Hell.'

I replied, "I have been to Hell and back and back."

The Hell I was referring to is my daily minute-by-minute, hour-by-hour physical and mental battle with Parkinson's disease.

I know I have been to hell when I wake up at night, and my jaw is locked so firmly that I can't talk. My mouth is so dry that I could drink gallons and gallons of water and still be thirsty. The sounds that I produce cannot be understood. Fear paralyzes me as I wonder will I ever speak again. My legs feel as though they are being squeezed by a vice. Behind my kneecaps, there is a burning, aching feeling in both legs. My left ankle feels as though someone is striking me with a hammer. My arms are immobile. There is severe pain behind my left ear. The paralyzed fingers on both hands have formed a claw. The tips of my fingers feel as they are being pricked by needles. My vision is blurred. My eyes don't want to open Every time I breathe; it feels as though someone is hitting my back with a baseball bat. My lungs feel as though they want to explode. Tears roll my cheeks as I curse these symptoms.

My Story

Parkinson's Disease (PD) is a neurodegenerative brain disorder that leads to shaking, stiffness, and difficulty with walking, balance, and coordination. PD is progressive with symptoms worsening as the disease advances. PD occurs when nerve cells in the substantia nigra, a part of the brain, die off. The first symptoms I saw were tremors in my left foot, arm and hand. Over time the same symptoms appeared on my right side.

Other PD symptoms are rigidity (causing muscle cramps and soreness), decreased dexterity and coordination, Bradykinesia (slow movement) and muscle weakness causing problems with swallowing, choking, drooling, voice changes and stuttering. Other PD symptoms include loss of smell, hallucinations, memory loss, delusion and depression.

The American Parkinson Disease Association (APDA)

says, "Approximately 60,000 Americans are diagnosed with PD yearly." This number does not reflect the thousands of cases that go undetected. An estimated 7- to-10 million people worldwide have PD. One million people will have PD in the U.S. by 2020, according to APDA.

Eight years ago, when I was told I have PD I was shocked and numbed. In my 36 years working in the disability arena, I had worked with people with PD. I had seen them during their best and worst "periods". Knowing there is no cure for PD, I decided to assemble an arsenal of weapons to defeat PD or fight it to a draw.

I am determined to make sure that PD does not conquer my spirit. I intend to keep my body moving, my mind expanding and productive, and to obliterate obstacles that PD throws at me. I intend to leave this life walking straight as an arrow

When I told my wife Lisa and our three children I have PD, no one cried. Lisa said, "We are in this situation together. We will get through this together."

PD's Five Stages

There are five stages of PD. I have experiences with stages 1 to 4. In Stage 1 tremors developed in my left leg and foot, hand and arm. I began limping. This situation lasted for a year. Then tremors appeared on my right side. The tremors made walking, showering and dressing difficult. The tremors in my feet occasionally prevented me from putting shoes and socks on.

In Stage 2 there were more episodes of tremors and rigidity (freezing), happening multiple times a day and lasting for hours. When rigidity happens people with PD feel as though their feet are frozen to the ground. Walking was painful and difficult. I started losing my balance and falling. Medications had little effect. I was depressed and angry. I sought counseling.

Stage 3 has been the most difficult period coping with PD. I move slower. It takes me longer to write, dress and walk. Maintaining my balance is a major challenge. Hallucinations started three years ago and continue. When I am in the kitchen, standing to the left of the refrigerator with my back facing the sink, a shadowy, bodiless face, covered feminine figure appears on my left side about two feet above my shoulder. She is looking

down at me. She is speechless. She stays there until I leave. I don't speak to her. She appears three and four times a day. I see other bodiless figures during the day.

My worst horrifying hallucination is my weekly recurring dream of standing outside of the Gates of Hell. My body is intact. Inside the open gate, I see a slim, facially disfigured, legless shadowy figures moving about and bumping into each other. The figures are clothed in loose, long-fitting white T-shirts. I see flames leaping higher and higher into the air. I feel their heat. And I hear ear-piercing screams. There is a putrid smell of burning flesh. The shadowy figures are screaming as they realize they will be there for eternity and as flames reach them. Each figure is voiceless, except for their screams. Some screams are louder than others. Each figure is so disfigured that they can't identify anyone – relatives or friends. I watch as more figures enter the Gates of Hell. Their numbers raise the volume of screams coming from inside. I can't tell the gender of the figures. I hear the echoes of their screams. They are so loud I am surprised I am not hearing-impaired. As I continue to watch this nightmare, I ask myself, "Why I am here witnessing this horror?" As I ponder this question, I wake up. Each dream seems longer than the previous one. I hate this dream.

In 2017, I started hearing Jazz music in my right ear many hours no matter where I am. The music makes it difficult for me to hear people's questions. When I first heard the music, I checked my computer, TV, cell phone and radio to learn if they were on. They weren't. I know the music is not real, so I focus my attention elsewhere. The music is annoying. It has gone beyond Jazz. I hear different types of music and people singing. Eventually the music stops. It angers me that I can't turn the music off.

Since 2017 I have been experiencing short term memory loss. When I am asked questions that I know the answers, I can't remember the answer for 5 to 10 minutes. Memory loss consumes me. I see a time in the future when I could have total memory loss. Every day I pray and pray that PD will not progress that far. If my mind is dead, I am not living.

Long-Term PD Care is Expensive.

Long term care for people with PD is expensive. I am covered under Lisa's health insurance policy with Anthem-Blue Cross-Blue Shield, and I have Medicare.

My advice to everyone is if you don't have health insurance, buy it and make sure it covers long term care. The price for treating PD is astronomical. Last year, Anthem and Medicare, just for me, paid more than \$162,000. The money covered multiple doctors' visits, medications, X-rays, physical therapy, five operations and home visits by nurses. This year Anthem and Medicare may pay more than \$162,000. My medications are more

than \$10,000 a month. If I had to pay for my medical expenses, I would be living on the streets or dead.

Anthem and Medicare cover physical therapy. To combat PD, I exercise two hours daily. Physical therapist Kevin Linde branded this message in my brain, "Keep those muscles moving." When exercising, I hear Linde's advice, "Keep those muscles moving."

My daily exercise routine involves walking 2 miles a day, riding my exercise bike 15 to 30 minutes, bouncing a tennis ball 50 times with each hand. I put a tennis ball in each hand and flick each wrist 50 times. I use a hand grip in each hand 75 times. I take a 3-foot rubber rope, knotted at each end, and stretch it as far as I can extend both arms 30 times. I do 125 leg exercises.

I have physical therapy twice a week. Linde and I work on mobility, balance, rigidity, tremors and strength. Physical therapy helps me retain mobility, reduces rigidity, stiffness and tremors, strengthens my leg muscles, improves my cardiovascular system and keeps my weight down.

Nearly every morning when I wake up, my legs are so stiff that I can't walk; and sometimes my jaw locked so tight that I can't speak. I lie in bed and begin exercising my legs, hands, arms, jaw and neck. It takes a lot of mental energy to start my exercises. Once the muscles start moving, I keep them moving.

To unlock my jaw, I take a big bite of a green apple or hard peach and start chewing slowly. A few minutes later my jaw is unlocked.

There are situations in which I am not mobile, then I use one of my two wheelchairs. I use a walker to prevent me from falling and for leg and arm exercises. I learned a valuable lesson regarding the importance of a walker in my life.

One Saturday morning three years ago, I was walking around a pond near my house without a walker. Suddenly, my left leg buckled. I hit the concrete ground like an exploding shell. Blood was on my forehead and hands. I was in a lot of pain. I shouted, "Help! Help!" No one came. I picked myself up. An adrenalin rush struck me as I ran to my condo; I opened the door and shouted, "Lisa. Lisa. Look at me."

She jumped off the couch and ran over to me. She cleaned me up and drove me to the hospital. The hospital staff finished cleaning me up and took X-Rays. The X-rays showed the smallest finger on my left hand was broken. Now my walker or wheelchairs goes where I go.

The Caregiver Experiences

Six years ago, I realized that I needed a caregiver four

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days a week. I called local agencies that supplied caregivers whose primary responsibility is to keep me safe.

My experiences with caregivers taught me that a majority are poorly trained and under educated and know very little about PD. Three of the caregivers the agencies sent did not speak English. At least three caregivers thought I was totally immobile. They were shocked to discover I wasn't. I fired three caregivers because when I needed them, they were sleeping, talking on the phone or had gone out without telling me. Several thought that I had to obey every order they gave. For many caregivers caring for me was a second job. If I was writing, they napped. About 1/3 did not drive. Most of them stayed a couple of months, and then they moved on. I was always breaking in a new caregiver which can be physically and mentally exhausting.

Of the 23 caregivers I have had, there is one standout. Addis Tigabu is an exceptional caregiver. Born in Ethiopia, she became an American citizen last year. On a scale of 1 to 10, she is 11. Tigabu had experience

working with patients with PD before she came to me. How was she different from the other caregivers? She arrived on time. She knew the daily obstacles I faced and discussed them with me. She encouraged me to exercise, to write about my battles with PD and to think positively about my situation. She said she had patients with PD who don't do anything to fight PD. She admired my dedication to defeat PD.

When Addis knew I had a doctor's appointment, she made sure I was ready. If I had not shaved in days, she would politely say, "May I shave you?" Sometimes she helped me get dressed. She combed my hair and suggested I wear matching clothes. I have five doctors, so when we went to see them, she took notes and asked them questions

She knew when I was depressed and at length discussed the cause of my depression. She walked with me every day. To help Lisa, she washed our clothes, made supper on occasion. She baked cakes several times a week. She has a strong background in informa-

tion technology. She is in her mid-thirties, single and beautiful. She has a terrific sense of humor. I often teased her about the lack of men in her neighborhood and church for not pursuing her. I said, “The men in your neighborhood and Church wore blinders because you are too beautiful to be single.”

With a smile she would look at me and say, “Mr. Williams, I am doing fine.” Her smile was always there.

She admired Nelson Mandela. We had many talks about political leaders.

Tigabu is religious and family oriented. Frequently, we discussed religion and families. Her religion gives her empathy for the sick and people with disabilities, that I have seldom seen in people. She has magic hands. When I was in a lot of pain, she gave me back and leg rubs to ease the discomfort. When she learned I had decided to have the Duopa procedure done, she discussed the pros and cons of the procedure for hours. She called me the day after the Duopa procedure to find out how I was doing and asked me if I needed anything. She showed me she was interested in me as a person. I never felt I was her patient. I felt she was family.

Tigabu is independent and a straight talker. She has an incredible knowledge of computers, both hardware and software. She is an excellent researcher, a strong organizer and an outstanding manager. She was my caregiver for eight months. She left to care for a man who was in dire need of her services. She was better medicine than all my medications combined.

After a year, we reconnected. We are staying connected. The word humanitarian can be applied to her.

Fighting Back Against PD—Enter Duopa

I have broken both arms and both legs. I have been hit by a car three times. I was kicked in the face—been kicked in the face so hard that I missed three weeks of school. I have had the shingles and carpal tunnel syndrome. I had ulcers, and I had an infective cyst removed from the tip of my spine. I thought I knew what pain is. I didn't until Parkinson's disease entered my life

My most egregious complaint regarding my medical care for PD is the years I spent searching for a pain killer. I kept telling the doctors of the pain I endured every day for hours. Over the years, doctors prescribed Ropinirole, Mirapex and Neupro Benzotropine, Rasagiline, Xadago and Rytary. None of these medicines deal with pain. They deal with easing tremors, shakiness, stiffness, mobility, spasms and poor muscle control.

In November 2017, I met Dr. Fernando Pagan, associate professor in the Department of Neurology, and Co-Director, Movement Disorders Program, MedStar Georgetown University Hospital.

At the time of our meeting I was taking 31 pills daily.

Dr. Pagan suggested that I consider the Duopa therapy. Duopa is a treatment of motor symptoms for people with advanced PD. Duopa therapy is a gel infusion of Levodopa and Carbidopa. Levodopa is in a class of medication called central nervous system agents. It is converted to dopamine in the brain. Carbidopa is in a class of medications called decarboxylase inhibitors. It prevents Levodopa from breaking down before it reaches the brain.

Initially, Duopa's side effects scared me. They can include hallucinations, depression, suicide, heart attack, abnormal blood tests, uncontrolled sudden movements, unusual surges, progressive weakness or numbness or loss of sensation in the fingers or feet and even death. However, after talking to people who underwent the procedure. I decided in its favor.

Before starting Duopa I needed surgery. On June 18, 2018, I underwent the 30-minute Duopa procedure. The surgeon made a small hole (called a “stoma”) in my stomach wall and then placed a tube in my intestine. This allows Duopa to bypass my stomach and go directly into my intestine. A pump that I wear 16 hours daily is connected to the tube. I wear a vest that conceals the pump. I can wear pump in a pouch on my left side.

As an outpatient, I was in and out of the hospital in seven hours.

Three weeks after the first Duopa operation the tubing came out of my stomach. I had a second Duopa procedure 10 days later. In September, the pump stopped working, and I had a third Duopa procedure. I have not had a fourth procedure. I am told I may have another Duopa procedure done next year. The tubing has to be replaced once every two years to stay effective.

It took 60 days from my third Duopa procedure before I reaped benefits from the Duopa procedure. Duopa has reduced, not eliminated, the number of freezing incidents, stiffness and the pain severity. Other benefits include walking faster and farther, sitting longer, working longer, sleeping longer and exercising more. I feel better physically and mentally. Duopa has improved my quality of life.

There are times when Duopa has not worked for days, and the PD symptoms return. And I am back in hell. A fall, a stumble, a slip, sitting too long, a cough can interfere with the Duopa flow. The interference can last 20-to-30 minutes or hours. Sometimes it takes days for the Duopa to get back to an even flow. When this happens, I push an extra dose button on my pump that most of the time works.

Duopa has to be refrigerated. Every morning at 7:00 Lisa takes the Duopa gel medication out of the refrigerator.

ator. She lets it defrost for 15 minutes and enters my bedroom to reconnect the pump to the stomach tube. She grabs a pair of tweezers and a tissue and slowly picks out the crust and a yellow liquid that developed during the night around the tube coming out of my stomach. I have lost plenty of chest hairs while she is cleaning around the hole. If the tweezers or tissue penetrate the hole, I get immediate pain. She cleans two tubes by injecting carbonated soda in them. Then she connects the Duopa cassette tube to the tube coming out of my stomach. When that task is finished, she programs the pump to deliver the medication constantly throughout the day. She duplicates the cleaning procedure in the evening when she disconnects the pump.

While waiting for the second and third procedures, I returned to swallowing 31 pills daily and to frequent freezing episodes and pain. I never wanted to become addicted to medication, so I am careful not to take more pills than necessary.

Before going to bed, the pump is separated from the 8-inch-long tube protruding from my stomach. The tube is capped. I take 11 pills to help me sleep and to deal with freezings while sleeping. Like a precision Swiss watch, every night between 2:15 and 2:45, I wake up with stiffness in most of my body and pain. Four pills and a large container of water are on a small table near my bed. If I can reach them, I take the pills and drink a lot of water. If I can't move, I push button on my bed rail to call Lisa to give me my nightly medicine. Either I fall asleep immediately after taking the pills or I am awake the rest of the night. If I can't go back to sleep, I grab my iPad or Kindle and either read or watch a movie.

There are times during freezing episodes at night when I tell Lisa, "I don't want to live this way."

Her reply is, "John, there are no whiners in this house." She smiles when she makes that statement.

The Downsides of PD

Every minute, every hour, every day PD challenges me. I detest PD. I want to see its demise to end its cruelty. I have endured many down sides with PD. I voluntarily gave up driving, out of my fear that I could cause a serious accident if I had a freezing episode while driving. I am a man who loves driving. When I drove, I was my own boss. If I wanted to go fishing, I got my gear and went. If I wanted to drive into Washington, D.C., I would ask my family if they wanted to go. I would go alone or take a family member. When I needed new clothes, I would buy them.

I don't have that luxury today. I have to depend on others to take me where I want to go. Too often I wait days or weeks before someone takes me where I want to go. I get very angry when this situation occurs. Losing my

independence depresses me.

PD has weakened all my senses and me, physically and psychologically. I have battled tremors, rigidity, muscle cramps and soreness, decreased dexterity, memory loss, hallucinations and Bradykinesia. I have survived pain that put me in a state of unconsciousness. I have trouble swallowing, choking, drooling, coughing, sporadic memory loss, and depression. I have had the same severe cough for three years. Eye surgery was postponed twice to because PD was out of control.

PD has robbed me of tens of thousands of dollars because I could not cover assistive technology conferences for news organizations and perform other communication tasks. PD has caused me to doubt my sanity. It prevented me from attending my daughter's wedding 6 years ago in Korea.

PD gives me dry mouth and locks my jaw. Too often, dry mouth appears when I am talking to someone on the phone. In extreme situations, dry mouth increases my stuttering during telephone calls. The combination of dry mouth, stuttering and a locked jaw makes it impossible for me to be understood. Therefore, I have to return the call.

I still have nights when I wake up and discover my whole body is so stiff that I am immobile, speechless and scared that PD has won. When this situation occurs, I call on God to help me. I need to summon strength to get out of this situation. It may take an hour, 90 minutes or two hours of activating one muscle, then 2, then 3 and so forth until I am mobile. It's a struggle, but it's one I have to win.

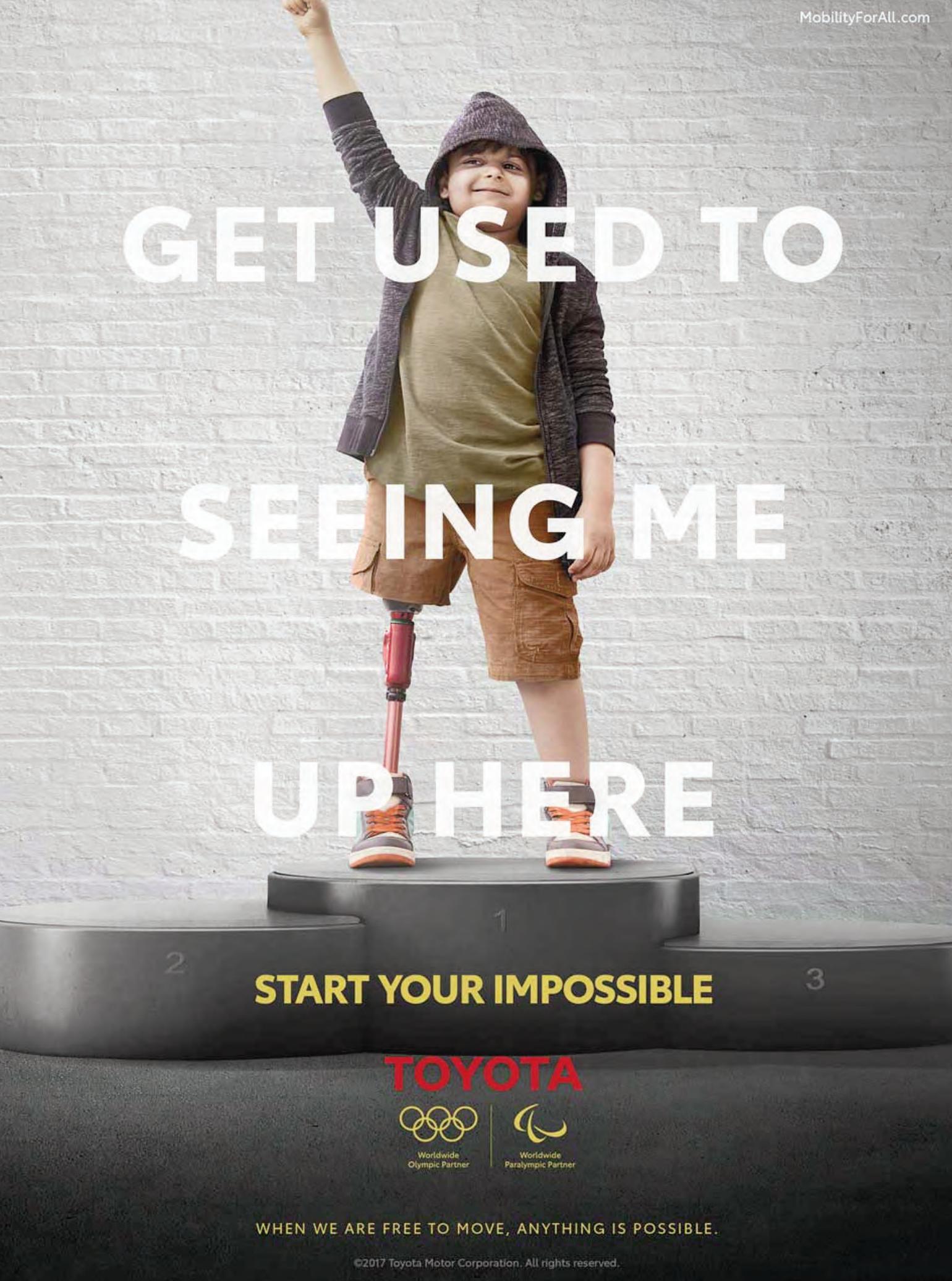
The moral support that I receive from family and friends is medicine to me. I could not survive without Lisa's assistance and my children; Sean, Faith and Brandon. Lisa's stamina awes me. She is a wife, bread winner, mother, grandmother of 3 children and my evening and morning caregiver. My ego soars knowing hundreds of people are praying for me. If the medical profession can't cure me, then maybe prayer can. God are you listening?

I have spent many, many, many evening hours on my knees praying. I ask God to cure me.

I am determined to make sure that PD does not conquer my spirit. I intend to keep my body moving, my mind expanding and productive and to obliterate obstacles that PD throws at me. I intend to leave this life walking straight as an arrow. ■ **ABILITY**

John M. Williams is an award-winning writer. He has spent nearly 40 years covering disability and assistive technology products. He coined the phrase "assistive technology."

atechnews.com

A young boy with a prosthetic leg stands on the first-place podium of a three-tiered black award stand. He is wearing a grey hoodie, a green t-shirt, and brown cargo shorts. He has a red and black prosthetic leg on his right side and is smiling with his right arm raised in a victory gesture. The background is a light grey brick wall. Large white text is overlaid on the image.

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SEEING ME
UP HERE

2 1 3

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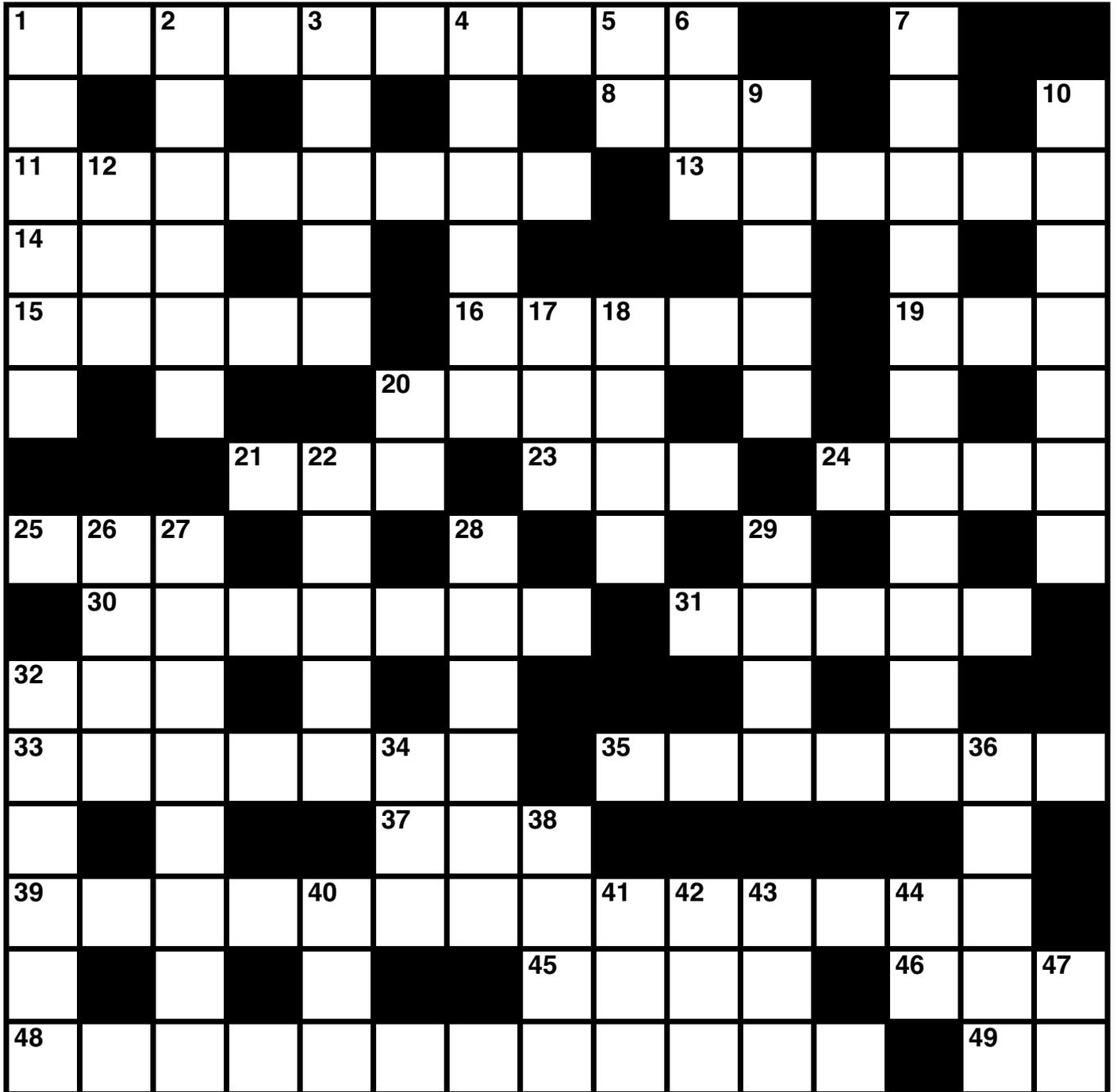
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ABILITY'S



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ACROSS

1. "Young and the Restless" star and national spokeswoman for the ALS Association, 2 words
8. NFL star whose foundation has developed programs to assist people with autism, ___ Marino
11. First African American to play in the MLB
13. Director who launched the reality TV genre, who recently created a number of shows about people with disabilities, Jonathan ___
14. Shirt sleeve
15. People who work together for a common purpose
16. Adores
19. Word with "dog" or "banana"
20. Descartes of philosophy
21. "The Accountant" star who works with charities for autism, ___ Affleck
23. Had some food
24. Girl in a Beatles song
25. Stubborn animal
30. "The ___ of Happiness," film based on the the career of a homeless man who changed his fortunes
31. Cat noises
32. Tree juice
33. Rule of personal conduct
35. Journalist and disabilities activist who writes for Huffington Post, 2 words
37. Good name
39. Supermodel with the Ford agency who is dedicated to find a cure for MS, 2 words
45. Italian dish
46. Time sheet units (abbr.)
48. Web series created by Donna Russo and Peggy Lane which describes Donna's life as a person with disabilities, 4 words
49. Greeting

DOWN

1. Movie "kid" who fights back against bullies
2. She escaped slavery and became a leading abolitionist, Harriet ___
3. Returns to earth
4. Pasta piece
5. Environmental activist, Begley
6. Ewe's mate
7. Show created by 13 across about young adults with Down syndrome, 3 words
9. Clara Barton was a famous one
10. Para___, Trisha Zorn
12. Rock
17. Stop ___ dime
18. They care for animals
20. Nurse, abbr.
22. Dairy spokesperson
26. Duke it out, in practice
27. Christopher Reeve's character
28. Perk up your ears
29. Oscar winner Sean who supports the charity "Believe in Dreams"
32. Momentarily let one's attention wander
34. Favoring
36. One of the Three Stooges
38. Lively and jaunty
40. Nutritional abbreviation
41. Oom-___ (tuba sound)
42. Mature or ripen
43. Persian product
44. What?
47. For that reason

answers on page 70

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

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- Actors & Celebrities
- Olympic Athletes

FOR PATIENTS

18-45

- Thin Flap Lasik
- ICL

FOR PATIENTS

45-65

- Superlasik
- Pi in Eye

FOR PATIENTS

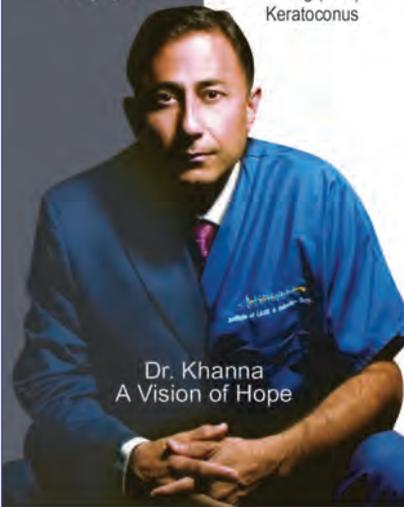
ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

OTHER THAN

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- Intacs & Cross-linking (CXL) for Keratoconus



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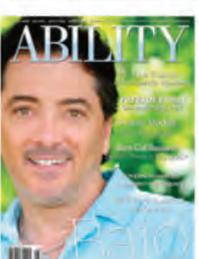
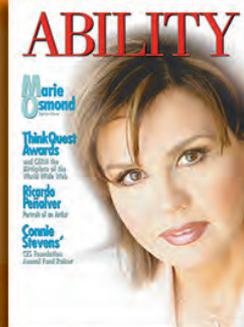
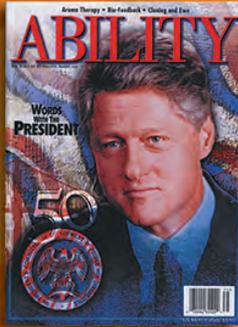
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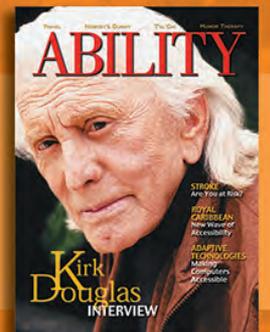
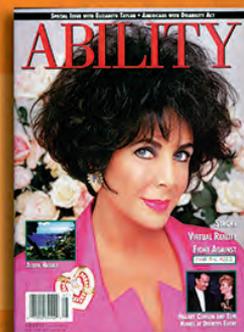
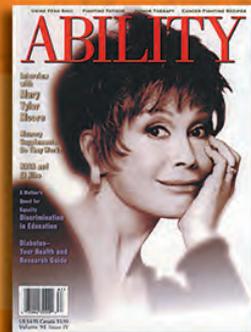
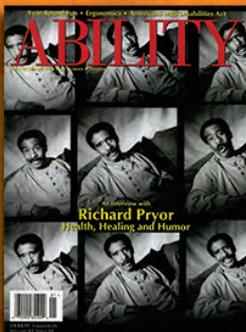
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