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Caregivers During COVID Hollywood Fails Jim Weisman

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'Our IVF Journey'

55 RETRIEVED
38 MATURE
15 FERTILIZED
11 DEVELOPING
2 TO TESTING
1 BEAUTIFUL BABY
♥ ILA MARIE
10/12/2020

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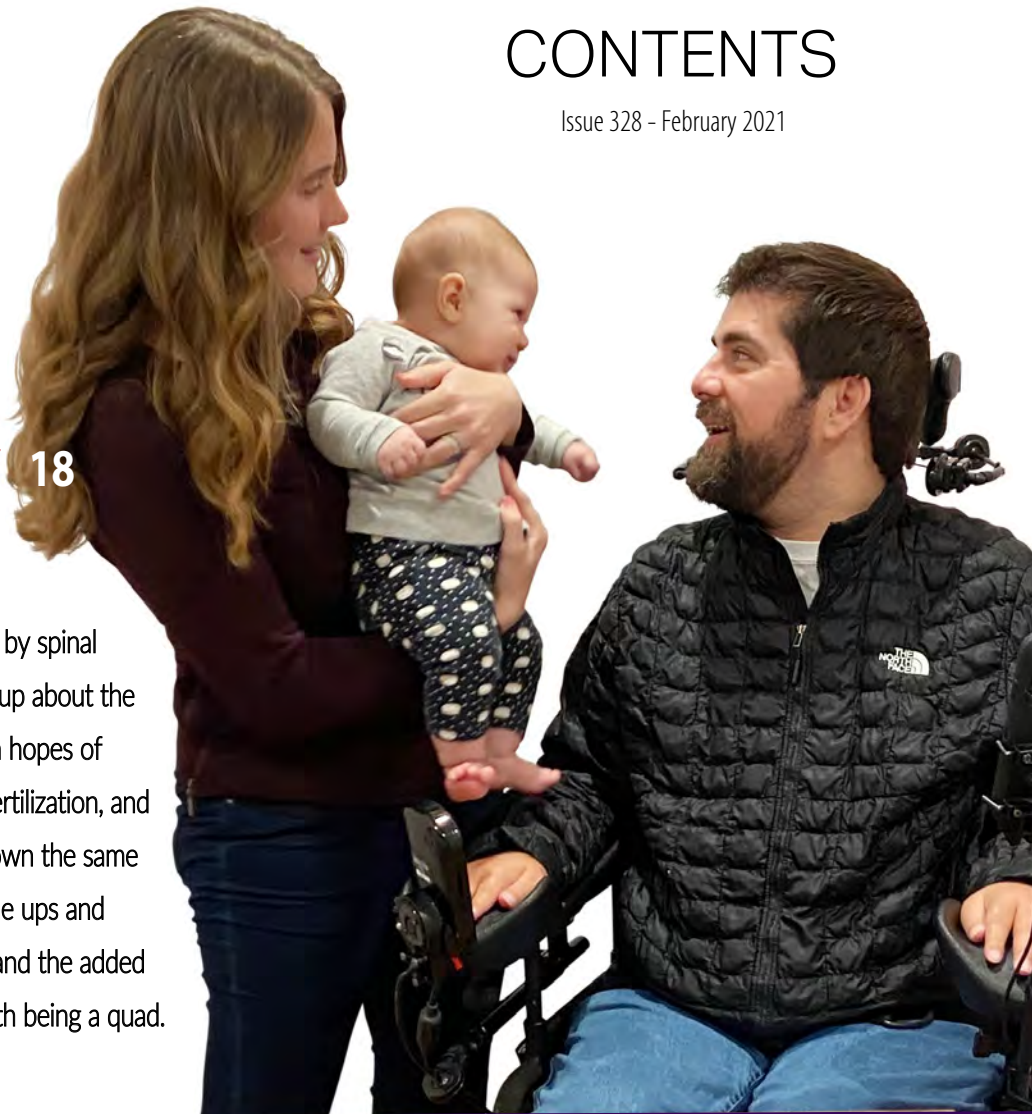


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COVER STORY

OUR IVF JOURNEY 18

In this year's Sex, Wheels & Relationships issue, we focus on the beginnings of two journeys affected by spinal cord injury. KENNY SALVINI opens up about the long road he and his wife traveled in hopes of having a child together via in vitro fertilization, and he talks with others who've been down the same path. ALI INGERSOLL documents the ups and downs of her first year of marriage and the added emotions and logistics that come with being a quad.



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14 A CAREGIVER LOST As the nation learned the dangers of COVID-19, one New York City quadriplegic and his longtime caregiver got a firsthand lesson in just how devastating the virus could be. IAN RUDER reports.

29 JAMES WEISMAN'S LEGACY SETH MCBRIDE chronicles James Weisman's decades of service to the disability community and his reputation as one of the smartest and most passionate advocates for accessibility.

34 HOLLYWOOD FAILS SYLVIA LONGMIRE examines Hollywood's all too common faux pas when portraying wheelchair users. MAT BARTON and ADAM COOPER's comic skewers SCI "rehab" in the current Netflix hit *Cobra Kai*.

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BULLY PULPIT

By Ian Ruder

VACCINE QUEST

In the crazy times we live in, I mistakenly thought figuring out when I'd be able to get a COVID-19 vaccine would be easy. Federal and state leaders and experts have been talking about the vaccine rollout for months. After almost a year of masks and isolation, getting vaccinated is the number one thing on pretty much everyone's mind. Determining when I would be eligible and how and where I'd need to go didn't seem like too big of an ask. I should have known better.

Let me preface this by saying I had no expectation of receiving a vaccine quickly. While I am a quad and a wheelchair user, I'm healthy and in good shape. I'm not over 65. I'm not immunocompromised, and I'm not an essential worker. There are a lot of people who need vaccines before I get one, and I'm fine waiting. Additionally, vaccinating tens of millions of people is an unprecedented and overwhelming task, and based on the way our government has struggled to respond to the virus to date, I wasn't getting my hopes up for a miraculously speedy rollout.

All I wanted was some certainty — a sense that there was a clear plan and an understanding of how I fit in it. Certainty has been hard to come by in the pandemic era and its absence has taken a toll on our mental health. Many of us have made all the recommended sacrifices and endured the accompanying hardships with the knowledge that there are no guarantees when it comes to getting COVID-19. You can do everything "right" and get sick, and you can do everything "wrong" and stay healthy. Even more frustrating, there's no way to predict how your body will respond should you get sick, with many people experiencing few to no symptoms while others see their lives destroyed.

So yeah, being able to lock in a date and a plan for getting the vaccine and finally knowing when this stage will be over would be a

nice change. Unfortunately, a month into the rollout, this still feels like a distant fantasy.

I started my quest for certainty on the website Oregon built to answer all COVID-related issues. I naively assumed there would be an infographic or chart that clarified the state's classification system and where I fit in it. Instead, I ended up trudging through a multi-page FAQ full of footnotes and obfuscations that left me even more confused than when I started.

You can imagine my relief when I noticed a small pop-up icon that identified itself as the "Vaccine Information Tool" and promised

"You can imagine my relief when I noticed a small pop-up 'Vaccine Information Tool.'"

to help me determine when I could get a vaccine. Unfortunately, as soon as I answered the two questions it asked, it immediately blurted out that I am not currently eligible. That I got the same result no matter what answers I gave to the questions made me think it might not be the best guide.

Everything on the website reenforced a sad truism that we as disabled people know all too well: Our own government doesn't understand us, and its ignorance often ends up directly harming us. Each state has its own plan, and I've seen some states handling the vaccine more efficiently, but more often I've heard of friends and other wheelchair users facing the same confusion and frustration I have.

While I did get a small laugh out of the Vaccine Information Tool's ineptitude, the vaccine rollout is no laughing matter. Over 400,000 Americans have already died from COVID-19, and if we don't start to get our act together, a lot more will follow for no good reason.



BEHIND THE STORIES

With Ian Ruder

Kenny Salvini's cover story provides a candid look at the exhausting, but ultimately rewarding, in vitro fertilization journey that led to the conception and birth of his beautiful daughter, Ila. In addition to writing, Salvini serves as the director of The Here and Now Project, a Washington state-based nonprofit that supports the SCI/D community. I know how busy that position keeps him, in addition to his daily life as a C4 quad, which adds another level of appreciation when I consider all the hoops he and his wife, Claire, had to jump through. "There were a lot of ups and downs," he says, "but you can't put a price on the reward at the end."



If you follow any of **Ali Ingersoll's** social media accounts or read her writing here or on her blog, The Quirky Quad, you know there are few — if any — topics too taboo for her to take on. "I've never been shy," she says. In this issue she opens up about the first year of marriage and some of the novel challenges facing couples when one partner is disabled. The pandemic presents new obstacles for all couples, and Ingersoll jokes that she is glad she and her husband got most of their first year in before the lockdowns began. "I'm so ferociously independent," she says, "If he would have had to stay home all the time, I would have killed him."

You might think a pandemic would be catastrophic for a travel writer, but **Sylvia Longmire** isn't one to just sit around doing nothing. She published her latest book, *Blogging While Disabled: How to Make Money Writing from a Wheelchair*, in May, and has kept busy with voiceover work and acting auditions. She has also built a loyal social media following, creating witty TikTok videos and cohosting "The Dish on Disability," a weekly conversation on Clubhouse, a hot, new social platform. "It's great to see so many more people talking about and starting to see the breadth of diversity and that it involves people with disabilities and being authentic about them," she says.



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Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org

DECEMBER 2020

'2021 Consumer Guide'

The Flying FreeWheel: I love my FreeWheel and have also found it transformative ["Refining Your Manual Wheelchair"]. I live in New York City, and it is great at going over lousy sidewalks and bad curb ramps. Also, it makes small jumps much easier, like hopping across the gap getting on a subway. My speed is about doubled.

My younger boy spent a couple years riding around in my lap. We did get tossed out of my chair once due to the FreeWheel's hook getting caught on a metal basement access door that protruded too much into the sidewalk. I have since trimmed the hook on the back of the footplate so it is not as close to the ground. A Dremel or hack saw does the trick.

Jim Felakos
Newmobility.com

Send Your Dragon to Boot Camp:

I noticed that you use Mac. Do you use Dragon on Windows in Boot Camp, or through a virtualization tool like Parallels ["Making Technology Work for You"]? I've used it in Parallels, but it runs very slowly. I'm curious if it runs better in a Boot Camp environment. I'm also concerned that the new Mac processors won't support Boot Camp, which will limit our options.

Emmett Lyman
Newmobility.com

Author Michael Franz responds: I've used Dragon with both Parallels and Boot Camp. In my experience I've found Boot Camp to be better for Dragon but it's not

"I'm extremely upset at how hard I laughed at this."

as good as I would like. I actually have a Windows laptop just to use Dragon with. I share your concerns about the new Mac processors. From what I've read, Boot Camp doesn't work with them. I hope that there will be new dictation software for Macs, as I prefer to use them.

Make Your Own Tools: I have limited use of my left hand and use a wrist brace when I hold a blow dryer ["Five Tools to Increase Independence at Home"]. I've recently started using a vertical L-shaped wood piece I asked my husband to make to rest my arm against for elbow support. It's so simple and cheap to make, but now I can't do without it!

Sharon Fasnacht
Newmobility.com

Editor: For more reader suggestions on DIY tools, read the comments after the article at newmobility.com/2020/12/five-tools-to-increase-independence-at-home.

'Smart Chair Wins the \$1 Million Toyota Mobility Challenge'

Phoenix Rising: I'm super-excited about the downhill braking assistance. We all know the pain of grabbing hot rims on a steep hill and having to hold on for dear life while our hands hurt like heck.

Meredith Marr
Facebook

Wow: How exciting! What an awesome development in wheelchair design.

Ubee Nutrition
Instagram



Keep it Simple: More unproven technology. In the middle of nowhere or the middle of the night when it breaks or fails, who do you call, who will repair it and what will be the time and cost? Simple may not always be the best but it always works.

George T. Janiec
Facebook

Editor: For more about the Phoenix i, watch this month's New Mobility Live interview with inventor Andrew Slorance on Facebook, Instagram, YouTube or newmobility.com. Also, see News Analysis, page 8.

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Meanwhile, on Instagram ...



www.matbarton.com

I'm extremely upset at how hard I laughed at this.

Ronel C

@mr_gramici

My friend and I call each other twin because folk keep mixing us up. She's in an orange powerchair and I'm in a manual chair. We're often going, "No. I'm the other black woman in a wheelchair."

Luticha Andre Doucette

@Freedomofmovement35

I was just thinking about this. My friends don't even recognize me if I'm driving and I wave at them. It's like they need my chair to know who I am.

Emily McQueen

@mcqueenmama

@wanderingarms [NM's Seth McBride] and I both have kids in the same preschool class, so I've been called Seth a few times. That's where the idea for this strip came from.

Mat Barton

@matbarton

Up Next in the March Issue:

The Fight for the Right Chair

Securing a wheelchair that maximizes your independence and comfort requires a long and often complicated process that involves therapists, doctors, wheelchair providers, manufacturers and — of course — insurance. Getting lost along the way is all-too-easy and can have a direct impact on your quality of life and health. Seth McBride guides you through his personal chair odyssey and shares insider insights so your journey can go more smoothly.



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By Seth McBride

SMART WHEELCHAIRS: THE FUTURE IS NOW

On Dec. 17, the Toyota Mobility Foundation announced that the winner of its \$1 million Mobility Unlimited Challenge was a smart manual wheelchair, the Phoenix i. The Phoenix was created by Andrew Slorance, a Scottish inventor and wheelchair user who had previously designed both the futuristic Carbon Black Wheelchair and Phoenix Instinct, a practical luggage system for wheelchair users.

Slorance's award-winning innovation is to add smart technologies onto an ultra-lightweight, carbon-fiber frame that blurs the lines between power and manual wheelchairs. It edged out four other finalists from across the globe — a Japanese team that developed a lean-to-move standing power wheelchair, an Italian team that designed a wheel-on shared

mobility device that wheelchair users could use as an alternative to the dreaded scooter-rental programs, a U.S. team developing an advanced exoskeleton, and another U.S. team that developed a powered calf-sleeve for those who experience foot drop due to a stroke or other neurological conditions.

For obvious reasons, the team at New MOBILITY has been most excited about the Phoenix, but all of us were a bit skeptical that Slorance would actually win. That a wheelchair, even a ground-breaking one, could win a contest seeking to usher in the future of mobility seemed a stretch. After all, when people outside of the community think about technology to get disabled people moving, they think about walking. History suggested smart money was on the exoskeleton. But the wheelchair — designed by a wheelchair user, no less — did win. And that says something about Toyota as a company and how the foundation designed the challenge, as well as Slorance's prowess as an inventor.

The Challenge

The Challenge exists because of a business decision Toyota made to shift away from focusing primarily on the automotive marketplace to designing for mobility on a broader scale — think autonomous people movers for sports venues, robot helpers, self-driving cars, exoskeletons for factory workers, battery-operated scooters and hydrogen fuel cell buses. Many of the concepts have been designed from the ground up with universal design and accessibility features. Toyota's R&D dollars seem to confirm the same long-overdue phenomenon also suggested by its commercials featuring adaptive

“Toyota's R&D dollars seem to confirm that major corporations are finally starting to view people with disabilities as customers rather than objects of charity.”

athletes and tantalizing glimpses of stair-climbing wheelchairs — that major corporations are finally starting to view people with disabilities as customers rather than objects of charity. “We're actually now becoming a market force,” says Rory Cooper, who runs the Human Engineering Research Laboratories at the University of Pittsburgh. “And that can only lead to more good things.”

The Toyota Mobility Foundation tapped Cooper and his colleagues at HERL to help design the Mobility Unlimited Challenge on one condition — they weren't allowed to compete. Cooper has been at the forefront of mobility product research and design for decades and one goal of the Challenge was to nurture the next generation of designers.

The foundation and its partner, Nesta, which ran the Challenge, did their homework. They decided to focus on lower-limb paralysis rather than limb-loss or limb difference, both because of the huge numbers of people who are spinal cord injured (the WHO estimates up to 500,000 every year), but also because “the market for prosthetics was more developed and already benefiting from cutting-edge technologies, whereas the highly segmented market for mobility devices for people with paralysis was less innovative,” as TMF explained in a

Andrew Slorance





Slorance, right, and composites engineer Jakub Rycerz show off the latest Phoenix i prototype. Stay up to date at phoenix-i-wheelchair.com.

Photos courtesy of the Toyota Foundation

post outlining the Challenge.

There are a multitude of reasons for the lack of innovation in mobility products, ranging from healthcare insurances that will pay for only the most basic products, to government regulation, to economic realities of wheelchair manufacturers being owned by multi-national conglomerates and private equity firms. "The culture of your business changes when investors come in. It becomes a business about how much money can you make and how fast can you make it," says Slorance. He says that the Toyota award allows his business to stay focused entirely on delivering a quality product. "Toyota doesn't take any equity. They don't retain any ownership of the [intellectual property]. They're literally saying, 'Here's a million dollars, go and do this. Go and make a difference for wheelchairs and wheelchair users.'"

The Winner

The Phoenix i, with its black matte carbon and graceful curves, certainly looks like the future. The look was both an aesthetic and a practical choice. For one, Slorance wanted to create something that he would feel good about rolling around in. Second, carbon fiber doesn't like straight lines and 90-degree edges. By designing to the material's strengths, Slorance has managed

to create a frame that, at 5.5 pounds, is as light as anything else on the market while being strong enough to stand up to daily use.

Anticipating the skepticism many wheelchair users have about new and complicated technologies, Slorance has designed the Phoenix i as a modular system. If you just want a slick, ultralightweight frame, you can have that. If you like the idea of self-adjusting center of gravity, you can add that on. Same with the power assist and auto-braking system, which will run through the front casters. (See newmobility.com/2020/12/andrew-slorances-phoenix-i-smart-wheelchair-wins-the-1-million-toyota-mobility-challenge for a more detailed breakdown of the chair.)

The frame has internal wiring and ports to connect these additions, and Slorance hopes that third-party designers will develop their own add-ons. A system that measures rolling efficiency and lets you know when your chair is in need of maintenance or another that lets you use an online mapping program to measure road conditions, slope and cross-slope to help fellow wheelchair users select the most accessible routes are all within the realm of current technologies.

The modular system is smart from a

reimbursement standpoint as well. "This is not a [\$15,000] dream for most people to never achieve," says Slorance. "It's going to follow an existing program — the chair will cost the same as your RGK [a British manufacturer of ultralightweight wheelchairs] and the add-ons will be cheaper than your SmartDrives, so we shouldn't face too many challenges getting reimbursement." That's under Britain's National Health Service though, and coverage under Medicare and many private U.S. insurances is likely to be a tougher sell. (For more on the state of wheelchair coverage in the U.S., see our upcoming March cover story.)

It is this kind of thinking that really sets the Phoenix i apart from the other finalists in the Mobility Unlimited Challenge. Slorance and team sought to design a product that is both practical and innovative. They understood how people with SCI/D use their chairs and the problems with existing technologies, and they know that wheelchair innovation doesn't benefit anyone unless you can figure out how to pay for it.

It really shouldn't be surprising that Slorance won. Wheelchair users have long known that most of the true innovations in mobility products have come from within the community. Kudos to Toyota for figuring that out too.

MEMBER BENEFITS

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United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.



NEWS FROM UNITED SPINAL

JOIN OUR 75TH ANNIVERSARY CELEBRATION

United Spinal Association began in 1946 when World War II veteran Robert Moss rolled his wheelchair into Grand Central Terminal in New York City and led fellow veterans in a passionate protest. The group simply wanted to reenter the society it had fought a war to save. In the 75 years since, United has kept up its fight for inclusion and equality for all people who live with spinal cord injuries or neurological conditions.

Since its inception, United Spinal has been a tenacious advocate for policy and regulations that have shaped how our nation defines disability and accessibility. From drafting the Americans with Disabilities Act to ensuring quality complex rehab equipment is available to providing wheelchair users direct disaster relief, United Spinal has been on the frontlines fighting to improve the lives of people with SCI/D.

Today, with over 50 chapters and 57,000 members, the organization is stronger than ever. Now is the time to celebrate.

United Spinal is excited to kick off a full year of events to honor the organization's 75th anniversary, and we want you to join us in the celebration. The year of festivities will highlight the organization's legacy and build the foundation for the next era of working together with our chapters to improve the quality of life of our members and all who live with SCI/D.

As the proud membership magazine of United Spinal, *NEW MOBILITY* will be your source for information on all the upcoming events and how to get involved. We're also working on a special 75th anniversary issue that will arrive online and in mailboxes in October. In the meantime, watch for ways to connect with United Spinal, make your voice heard and even win prizes.

For more on the 75th anniversary celebration, visit unitedspinal.org/75th-anniversary.





REFRAMED

by Reveca Torres

LOSING COUNT OF THE DAYS

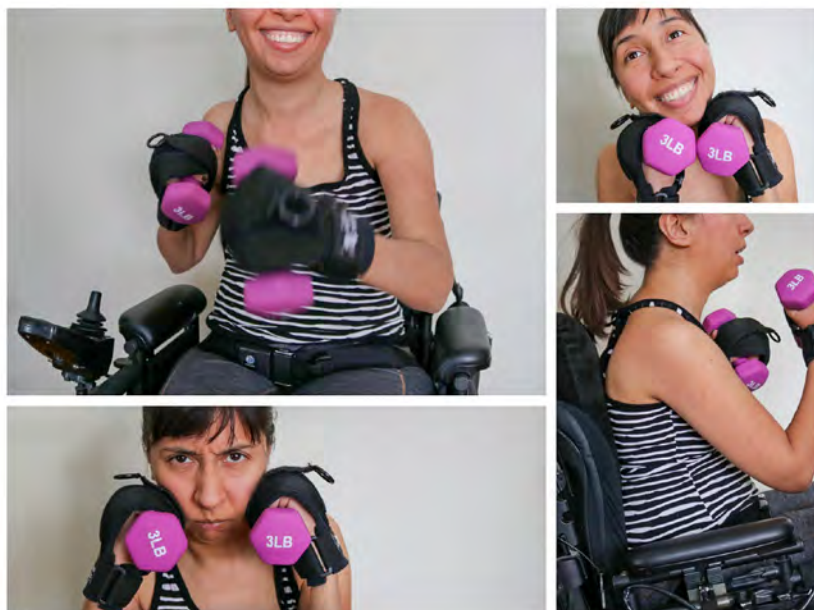
Two, three, four, five ... 11, 12 ... I count and lose count. Rest. Repeat. I've been counting the days living through a pandemic, and lately I've also been counting exercises during my virtual workouts.

I like exercise. I always have, even before my injury as a teen. I would look through fitness magazines and curate my workouts, go for a jog in my neighborhood, or run up and down the stairs (my parents wouldn't buy a StairMaster and I wanted a nice butt). Fast-forward 26 years, I sit on my nice butt all day, nobody gets to see it but my caregivers, yet I still like a good workout.

My first taste of a post-injury, non-physical-therapy workout was as a student at the University of Arizona. They have a great fitness facility for disabled students, including assistants to help with equipment. It somehow made me feel normal again and not like a patient. Upon graduation I struggled, and continue to struggle, to find a gym with the same level of access. Equipment is not designed for wheelchair users, people stare, hiring trainers is expensive, and membership fees don't feel worth it if I only have access to a few machines or classes.

Today, gyms and yoga studios are closed, and virtual fitness classes are easily accessible. I happily work out from my living room with people from different parts of the country. The coaches adapt movements to different abilities. My family and friends can join, and it feels great to be able to share in elevated heart rates, sweaty foreheads and burning muscles even when experience and ability varies.

I drink water and remember to breathe. This is a new normal I gladly embrace as it makes it easier for me to lose count of the days and stay present.



“Virtual fitness classes are easily accessible. I happily work out from my living room with people from different parts of the country.”

CHILDREN'S BOOK AUTHOR

Philip Langellotti



Inspired by a passion for environmentalism and the sense that kids weren't getting quality educations anymore, Philip Langellotti wrote a children's book teaching scientific and disability awareness.



The Adventures of the Runaway Wheelchair

In 2019, Langellotti, a 72-year-old C5 hemiplegic from Harrison, New York, published his first children's book, *The Adventures of the Runaway Wheelchair: Into the Atmosphere*. The story follows Mikey, a precocious and scientifically-inclined pre-teen wheelchair user who learns about climate change and the importance of environmental conservation after being sent into space by his wheelchair when it comes to life one night.

Langellotti worked as a lab technician and adjunct lecturer in natural and criminal science at John Jay College of Criminal Justice in Manhattan, New York, until he was paralyzed in a 1982 car accident. The idea for the book started germinating in his head since the mid-1990s when he was a stay-at-home dad caring for his kids.

"My kids would be in the kitchen as I was standing at the sink washing a dish or putting my Italian culinary traditions into practice by cooking the family meal. I never like to lock my chair because I'm in and out of it 100 times a day. I would keep it right behind me, and it would start rolling away and the kids would say, 'Daddy, daddy! Your chair is running away,' and I would say,

'Thank you very much, but one of these days, I'm going to write a story about that.'

Fast forward to the early 2000s, Langellotti and his family were attending a wedding when a friend expressed a concern about the environment and the impact of climate change. Langellotti was unsure what he could do to make a difference, but his friend's comment stayed in the back of his mind. In 2015, he decided to write a book educating kids on the planet's plight and the threat of climate change.

The book also gave him an opportunity to express his frustrations about living with an SCI, while giving the reader an inside look at the monotony and daily routine that sometimes comes with being a wheelchair user.

"It was a chance to vent about what was going on inside and was somewhat cathartic for me," says Langellotti. "As a wheelchair user, everything is based on having all your ducks in a row. I had to make sure I didn't have any bathroom issues and I had someone with me if we were out. It's always complicated. Always."

IF I COULD CHANGE ONE LAW:

Medicare is my biggest headache. In all my years, they've only approved one manual wheelchair and one power wheelchair.



MOST ACCESSIBLE VACATION:

Cruises. My wife and I have been on nine cruises. We've gone to Alaska, the Bahamas, western Caribbean, Bermuda and Canada. It's easier for me and I can keep up.



Langellotti and his wife enjoy travel.

But more than that, he wanted to reignite his passion for teaching and his legacy as an educator, especially because he saw a lack of quality climate change books out there that were both educational and compelling to read for his target age group.

"This is a book for those age 13 to 99, and we're all going to be leaving this good earth behind. These young people need to know what they're inheriting, and what they have to read that's out there is mediocre," says Langellotti.

He worries that by not being in school because of COVID-19, kids are missing out on crucial tools that will take them through life. He hopes his book will broaden their horizons and help them open up a little. Though Langellotti is speaking to all students with *Runaway Wheelchair*, he's specifically talking to students who use wheelchairs.

"I want them to know that even though they are using a wheelchair, they can go places. I wanted to take that utilitarian object and make it bigger than what it is, so they can use their imagination to take them on adventures."

The Adventures of the Runaway Wheelchair: Into the Atmosphere is available on amazon.com.

Flower like an Orchid

Langellotti explains how the reflowering of an orchid resonates with him as a metaphor for finding a new life after SCI.

“ I have about 100 orchids and if I'm lucky, I'll have something in flower every month of the year. It's difficult for me to bring them in and out. Plus, it's cold in New York and you have to bring them in after the first frost, so I just leave them in the greenhouse. It's my joyful room that I can go to and just enjoy. I'm mostly at home, and growing orchids ensures I don't feel like I'm stuck. There's nothing better than flowering plants. It's very self-gratifying and brings me a lot of joy. I have plants in my greenhouse that are 30 years old. My orchids inspire me toward resilience. Like an orchid, I think you must reinvent yourself and maybe be reborn after injury. You have to pick yourself up, dust yourself off and start all over again.”



CAN'T LIVE WITHOUT: A left-footed gas pedal was a godsend. I brought my kids to school and I could get out and drive a little bit.

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Losing a Friend and a Caregiver: A COVID-19 TRAGEDY



BY IAN RUDER

Jose Hernandez hired Fausto Romero in 2008 as a temporary replacement for a live-in caregiver who had planned a trip home for the holidays. Fausto had just immigrated to New York City from Ecuador to be with his wife and children, and he had no caregiving experience. He did have a recommendation from Hernandez' current caregiver, and he was able to fill the needed shifts. That was enough for Hernandez, a C5 quadriplegic. "He was only going to be here for a month, and then I'd go back to my regularly scheduled programming," he says.

When Hernandez' caregiver didn't return from vacation, Fausto became his new primary guy. Over the next 12 years, as he worked long hours to help support his family of five, Fausto became much more just a caregiver for Hernandez.

He became a friend, a father figure and an integral part of his life. "Jose was his adopted son," says Antonio Romero, the youngest of Fausto's three kids. "He used to call him 'Jose Hernandez Romero' just to mess with him."

Fausto traveled with Hernandez on advocacy trips to Washington, D.C. He was there when Hernandez got his first job and when Hernandez bought his first car. The two even hung out when Fausto was off the clock, as Hernandez became a frequent guest at Romero family parties and barbecues. "He helped me evolve completely into a different person," says Hernandez. "I went from someone who wasn't working and played video games 18 hours a day to someone who works and drives and has some success in life."



During the worst days of the pandemic, Fausto commuted to work for Hernandez — until the day he couldn't. Here they explore Washington, D.C., during happier times.

From Ecuador to the Bronx

After almost a decade of living nearly 3,000 miles away from his wife and two of his three children, Fausto finally made it to the United States in 2008. Fausto had worked in construction and carpentry in his native Ecuador, and had turned a passion for photography into a career, working out of his own studio. He didn't hesitate to give that up to be reunited with his family in the Bronx.

Despite not speaking any English, Fausto adjusted to life as a caregiver quickly, according to Antonio. "It was a big change, but he just did it," he says. "It didn't even bother him. He could have left. He could have taken other types of jobs, but he really enjoyed working with Jose."

Fausto started working 24-hour shifts as a live-in and eventually moved to five 12-hour shifts per week. That allowed for plenty of time for him to bond with Hernandez and learn how to best work together. Their strong working relationship saved Hernandez time and worrying. "Once you develop that trust factor and synergy, you know exactly what the person wants before they say anything," says Hernandez. "It's so liberating because you're not sitting there trying to explain over and over again what you have to get done."

It helped that the two were just as much on the same page on a personal level.

"Living with someone four days a week in an apart-

"He was a father figure to me. He took me under his wing and treated me as one of his children."

ment is an intimate setting," says Hernandez. "You become family fairly quickly. He was a father figure to me because I didn't grow up with my father, and my mother had passed away when I was young. So, he took me under his wing and treated me as one of his children."

Antonio says the relationship Hernandez had with Fausto benefitted both of them.

"Jose started off picking up little bits from our culture, and my dad would pick up a little bit from his culture," he says. "They bonded and got along well. They might have

arguments, but the love was there. My dad loved the love that he got when he was working.”

The Virus Strikes

When the still-novel coronavirus began to wreak havoc in New York City last March, Fausto was one of the many caregivers who braved the empty streets to make sure their clients could live their lives. Five days a week he made the 45-minute commute to and from Hernandez’ apartment. On Friday, April 3, at the end of the shift, Fausto said the same farewell as he always did when he headed home.

“I’ll see you on Monday,” Fausto said. “If God allows me.”

“No, come on, stop with that,” said Hernandez, just as he did every Friday. “You’re going to be fine on Monday.”

“I’ll see you on Monday if God grants me another day of life,” Fausto responded.

That Sunday night Fausto called Hernandez to tell him he wasn’t feeling great but was still willing to come in the next day. He knew how difficult it could be to find replacements on short notice and didn’t want to leave Hernandez short-handed. Under normal circumstances, Hernandez might have taken Fausto up on his offer, but with daily casualty results skyrocketing and the constant drone of ambulances in the background, Hernandez erred on the side of caution. “I told him, ‘I’ll see you when you feel better,’” Hernandez remembers.

That would be the last time the two friends talked.

“His condition progressed so fast — it was probably in the lapse of three or four days, that he went from being perfectly fine to not being able to breathe,” says Antonio. Fausto asked for his son’s advice on whether he should go to the hospital as reports of overcrowding were scaring many away. He decided to go.

Doctors found blood clots caused by the virus in Fausto’s lungs and worked to dissolve them. Within three days he was on a ventilator. He passed on Easter, April 12, a week before his 63rd birthday.

“One of the last things that he said to me was, ‘You already know what to do. Just take care of your mom,’ says Antonio. “And after

that, the next day he passed away.”

Looking back, Antonio is glad his dad made the most out of his final year, returning to Ecuador to visit family and throw a party for his wife. “He enjoyed his last year,” says Antonio. “You know when people think someone might’ve known that this was their last trip? It was odd, because he went and he spent time with all his family, even the people that he wouldn’t normally speak to in his family.

He never did that, so it was a weird year for him to do all that all at once. ... He got to do what he wanted to.”

Hernandez will never forget the impact Fausto had on his life, both as a caregiver and a friend.

“Without Fausto, all the things I’ve accomplished would not have been possible,” he says. “Thanks to him I knew I had the support and help that I needed to be successful.” MM

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OUR IN VITRO FERTILIZATION JOURNEY TO PARENTHOOD

BY KENNY SALVINI

It didn't feel real until I heard the first cry echo out from the other side of the blue curtain in the operating room. After a nearly two and a half year journey, my wife, Claire, and I were finally parents to a healthy little girl, and I was mere seconds away from the moment all my dad-friends had been hyping up for months, when I would first lay eyes on my child and the whole world would change.

The anticipation was almost too much to bear. A million questions flooded my mind. Would she have my eyes? Her mother's perfect nose? Time stood still until the obstetrician hoisted all 12 pounds, 4 ounces of her above the curtain with a grunt and a chuckle, and the chorus in my head fell abruptly silent. My initial reaction was brief panic and my first thought was, "that can't be my kid."

Maybe I had seen too many switched-at-birth sagas on late-night TV, but given the circuitous path it had taken to get to that point, I couldn't put it out of the realm of possibility that there may have been some sort of mistake along the way. We knew when we first started exploring in vitro fertilization that it is emotional for any family, but the logistical wild goose chase that my spinal cord injury added to the process made it feel like anything could happen.

IT ALL STARTED WITH A PLAN

When I first woke up in the ICU at Harborview Medical Center 17 years ago and doctors told me that my snow skiing accident was going to leave me paralyzed, a C3-4 quad, for the rest of my life, I only had one question: Can I still


have children? Their hesitant response in the affirmative gave me all the hope I needed. I didn't put much thought into the actual process until a decade later, when the blue-eyed occupational therapy student I was flirting with said her greatest ambition in life was to be a mother.

My relationship with Claire was built on our mutual desire to be parents, but despite our best efforts in the bedroom over the years, we simply could not coax any of my little swimmers out the old-fashioned way. We knew we were going to have to explore other options, so we booked a consultation with the Men's Health Center at the University of Washington for the week between our wedding and our honeymoon cruise to Alaska at the end of May 2018.

The fertility doc advised us to forgo any further attempts to stimulate ejaculation with a vibrator like Vibrect or Ferticare, due to the high risk of autonomic dysreflexia and the low probability of retrieving usable sperm. Our best options were surgical, and we had two choices. The first, and least invasive, is called testicular sperm aspiration and the more involved is called microsurgical testicular sperm extraction. We decided to start with the less-invasive TESA in August 2018 and lined up Claire's egg retrieval with UW's women's clinic a month later. "We naively thought we would be pregnant by September," recalls Claire.

SETBACKS AND STRUGGLES

When my retrieval surgery only yielded 6,000 sperm with decent motility, we were a bit disappointed as, by compari-



A man with a beard, wearing a grey zip-up jacket, is seated in a wheelchair. He is looking towards a woman on the right. The woman has long blonde hair and is wearing a grey sweater and blue pants. She is holding a baby who is wearing a white patterned onesie and a yellow headband. The baby is looking up at the woman. In the foreground, a letterboard on a stand displays the following text: 55 RETRIEVED, 38 MATURE, 15 FERTILIZED, 11 DEVELOPING, 2 TO TESTING, 1 BEAUTIFUL BABY, a heart symbol followed by ILA MARIE, and 10/12/2020. The background shows a living room with a green wall, a peacock feather decoration, a lamp, and a patterned rug.

55 RETRIEVED
38 MATURE
15 FERTILIZED
11 DEVELOPING
2 TO TESTING
1 BEAUTIFUL BABY
♥ ILA MARIE
10/12/2020



Husband and wife share a kiss over their welcome baby bump.

son, a typical man's ejaculation results in millions of motile sperm. But we did our best to remain cautiously optimistic behind the theory that we only needed one to make a baby. We had the doctors pop those bad boys in their fancy freezer and put the focus on harvesting Claire's eggs.

Compared to the egg retrieval process, sperm retrieval looked like a leisurely afternoon stroll. Claire had to become a pharmaceutical expert almost overnight, juggling multiple pricey medications designed to hijack her reproductive system for the fertility specialists to work their magic, each medication with differing timelines, dosages and locations for administration.

Next came a seemingly endless string of appointments for blood draws to monitor her hormone levels and ultrasounds to track the progress of her ovarian response. "I was getting up at 6:30 in the morning to drive to Seattle for my appointments before work, giving myself injections in the car," she says. After a few calamitous tries at the subcutaneous belly shots of estrogen, she figured it out. Her body responded beautifully in September, producing 33 eggs, 21 of which were mature and ready for fertilization.

But when none of my sperm survived the thawing process, we were devastated. It had always been a foregone conclusion that I would be a father, and suddenly we were facing the stark reality that it may not happen. The fertility doc agreed to do a microTESE but counseled that the biopsy results meant we needed to prepare ourselves for the very real possibility that using my sperm may not be a viable option.

We reached out to a local physiatrist who is a fellow wheelchair user to get a second opinion, and he said there was anecdotal evidence that certain diets could aid the sperm generation process, called spermatogenesis. He advised me to adjust my medications and stop any supplements, like D-mannose, that may interfere. Instead he counseled me to add selenium, vitamin D3, vitamin E and astragalus root supplements to my daily regimen while snacking on copious amounts of dark chocolate and dark-colored berries in hopes of boosting my production.

Since spermatogenesis takes roughly 75 days from start to finish, we booked the microTESE for mid-January to give the supplements a chance to do their thing. Unfortunately, a December hospitalization for a UTI put me on IV antibiot-



THE GREAT SPERM HUNT

Studies have shown that only around 10% of men with spinal cord injuries are able to conceive naturally through intercourse. Thankfully for the other 90% there are a myriad of options, each with varying levels of invasiveness, effectiveness and potential side effects.

VIBRATORY STIMULATION

Vibratory stimulation is the most common method families try first. It involves applying a vibrator like the Viberec or Ferticare to the penis in hopes of achieving ejaculation. "They gave us the option to do it in the clinic, but we preferred to do it at home," says Max Woodbury, a C6 quad from a fall at work in 1996 when he was 24. He and his wife, Tali, had success with Ferticare, but it came with terrible autonomic dysreflexia. "It was kind of scary, because the headache was so intense. Way more than I've ever had from bowel or bladder [irritation]."



Max Woodbury and his boys

Collected semen can be used for artificial insemination, but because low motility is so common for men with SCI, many couples choose to use it for the in vitro fertilization method of selecting one good sperm to be injected into

each egg. "We tried artificial insemination half a dozen times before we were ready for IVF," says Woodbury.

ELECTROEJACULATION

Woodbury's Portland Ponders Quad Rugby teammate, Ed Suhr, hadn't had much luck with Ferticare when he and his wife, Trish, tried it in 2003. "Nothing was coming out," says Suhr, a C5 quad since a 1984 car accident. "Either it wasn't happening, or it was retrograde." Retrograde refers to backward ejaculation into the bladder, another common phenomenon for men with SCI. In those situations, the sperm must be retrieved from the urethra or bladder and washed with a chemical solution before being used for fertilization.

The couple was advised to try electroejaculation, where an electric probe is inserted into the rectum and positioned against the prostate to stimulate ejaculation by slowly increasing the frequency and amplitude of energy to the probe. The procedure is not as widely used these days because it carries a risk of rectal mucosal burns and awful autonomic dysreflexia. "That was kind of a nightmare," says Suhr, of his dysreflexic response. He thinks his blood pressure was 280/130. "We didn't try that again." One unsuccessful attempt was all he needed to move on to surgical options.

TESTICULAR SPERM ASPIRATION

Any mention of surgery and testicles in the same sentence is enough to make even a paralyzed man's legs spontaneously spasm closed. "It sounds like the doctor carves out a part of your testicle and then holds it up in a glass vial, saying, 'See this?' Tink, tink, tink," says



Ed Suhr and sons

Woodbury about TESA.

"The reality is a lot less graphic," says Ian Ralston, a former Army medic and C1 quad from a 2010 IED attack in Iraq. When he and his wife, Nicole, were looking to have kids in 2014, they settled on TESA to get the job done.

The minimally-invasive procedure is akin to a biopsy, where tissue and fluid are extracted from the testicle by using a needle with negative pressure. "They didn't put me under, they just gave me a couple of units of Versed that knocked me out really quick," says Ralston about the 30-minute procedure he underwent in 2014 that netted six vials of bankable sperm for later use.

Results can vary because of the blind nature of the biopsy. That is probably why I came to think of the TESA as trying to extract loose change from your couch by shoving the extension wand of your vacuum in between the cushions.

MICROSCOPIC TESTICULAR SPERM EXTRACTION

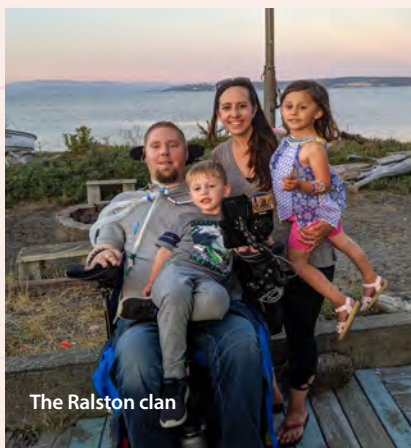
Compared to TESA, microscopic testicular sperm extraction has significantly higher sperm retrieval rates. Also it is a safer procedure since less tissue is removed.



DOUBLE TROUBLE: THE EMBRYO TRANSFER GAMBLE

When people think of in vitro fertilization, they may remember tabloid headlines and reality TV shows about families with whole litters of kids after they chose to implant five or more embryos. Turns out those cases are extremely rare, as most clinics will not let you implant more than two embryos unless the mother is above the age of 35 or has other pre-existing fertility issues. Although, since the odds of having identical twins through IVF inexplicably is 30% higher than those for a normal pregnancy, the chance of having multiple babies is still extremely high.

The Ralstons never intended to have multiples when they began the IVF process, but circumstances just sort of fell into place. Their initial cycle yielded two embryos of marginal quality, which they chose to implant, but neither managed to take hold. When a second cycle resulted in six good embryos, the couple once more decided to double their chances.



The Ralston clan

"We thought we were more likely to get pregnant with two than one," says Nicole. "I will say that we did not think we would actually have twins. Though, it was quite the amazing surprise!"

Transferring two embryos was also the standard procedure at the Suhrs clinic. The couple had eight viable embryos and chose to have two of them

implanted. "We were OK if we had twins if it doubled the odds of the procedure working," says Suhr. "Daniel and Conor were born in July 2004."

Watching his teammate's family effectively double overnight served as a cautionary tale for Max Woodbury. Babysitting the infant boys a week prior to their own embryo transfer helped the couple solidify their decision. "I was holding one, and Tali was holding the other, and I said, 'This could be a lot of work,'" he remembers. "We decided to transfer one embryo, just to be on the safe side." The universe apparently had other plans, as identical twins Noah and Levi were born in July 2005.

Suhr jokes that there must've been something in the Portland water supply at the time. "We had three guys that got IVF and in all three cases it worked first shot," he says. "So, we actually had three sets of twins on the rugby team."



Little Ila asleep in her father's lap.

ics, which wreaked havoc on sperm production, forcing us to restart the process and push the procedure out to March. In retrospect, we needed that extra time to wrap our heads around the idea of possibly needing a sperm donor.

Initially, we bristled at the thought of using someone else's seeds to start our family. I naturally couldn't escape the idea that it was a referendum on my manhood but did not anticipate that Claire would take it just as hard. "It sort of felt like cheating on you," Claire says. "I married you because I fell in love with the whole package, and suddenly we were trying to find the next best thing."

We wrestled with our options for a few weeks, including adoption, but ultimately decided that was a sperm donor of a different kind. As much as I struggled with the idea of not being a biological father, I didn't want to deprive Claire of the experience of carrying and giving birth to a baby.

SPERM DONOR TINDER

I don't know why we thought we'd have millions of donors to pick from. In reality we were choosing from a pool of a couple thousand, dispersed over a handful of websites that featured profiles of young men with pseudonyms like Dante, Neo, Timber and Rockwell. They were all broken down by height, weight, eye/hair color, genealogy and family health history, as well as a whole slew of additional information to

help us make our choice. But first, we had to cross-reference them with Claire's bloodwork screening to rule out any who might be genetic carriers for potential birth defects.

The big one we were advised to look out for was cytomegalovirus, a member of the herpes family that includes chickenpox, cold sores and mononucleosis. It's a common virus that mostly lies dormant after an initial infection, but women whose first exposure is during pregnancy have a one in three chance of passing it onto the fetus. The baby then has a 10 to 15% risk of complications like hearing loss, neurological abnormalities or decreased motor skills. As a pair of disability advocates with close friends living with all sorts of diagnoses, it felt weird to be in a position to eliminate those potential life paths.

We found ourselves digging deep into the remaining donors' essay questions, handwriting samples, voice samples, baby pictures and sometimes even photos of them as adults. The most surreal part of the profiles are the subjective descriptions written by the interviewers. Stuff like, "Donor 13547 is the epitome of a sexy man, with strong masculine features, broad shoulders and a muscular build. He has an attractive, rectangular face with a square chin, full lips, high cheekbones, tidy brows and dark eyes."

There is nothing like picking out a potential surrogate father to root out even your mildest insecurities as you grapple with which of his traits you want to prioritize. Did we want someone who closely matched my physical attributes and academic achievements, or the intangibles like my sense of humor, emotional fluency or other aspects of my personality?

To help narrow the field, we created a spreadsheet playfully titled "Spinder" where we weighed out pros, cons, differences and similarities, and prioritized the traits we wanted to pass down to the next generation. We ultimately settled on a donor named "Jack," and it was recommended that we buy two vials of his swimmers in case we would like to have a biological sibling sometime later down the road.

A MASTERCLASS IN MANAGING EXPECTATIONS

Fortunately, we didn't need Jack. In March, the microTESE

hit paydirt and retrieved 1.6 million sperm with moderate motility. That was enough to inseminate all of Claire's 22 mature eggs that were thawed in unison with the procedure and have five extra vials to bank for later if needed. That momentary relief was quickly tempered by a seven-day emotional teeter-totter as we awaited daily progress updates.

After day one, we had eight successfully fertilized eggs, or zygotes. They had six days to reach the full blastocyst stage, which usually happens between days four and seven. Once

they reach that stage, a few cells could be taken from their outer wall and sent for genetic screening to verify they were chromosomally "normal," thus dramatically increasing our chances of achieving a live birth.

The number of "good" embryos were cut in half by day three, and halved again by day five, and none of the remaining two made it to the final blastocyst stage to be tested. Suddenly we were back at square one with even more questions.

Was my sperm or Claire's eggs to blame for the lack of success? Did we want to try another round of egg retrieval? If so, would we use another vial of my sperm, Jack's, or

a combination of the two? Plus, there was also the financial aspect. Insurance had covered the TESA, but we'd already shelled out a lot on the microTESE, all of the hormones, Claire's egg retrieval and donor sperm. We had enough money stashed away to cover another round but were unsure how much more her body and both our hearts could take.

THE EMOTIONAL TOLL BUILDS

Whereas most nondisabled couples have the option to navigate their highly emotional family-planning efforts behind closed doors, the extra logistics that come with our situation made maintaining the privacy of our struggles much more difficult. It's easy to talk about your successes, but rehashing every unanticipated setback with an ever-widening circle of well-meaning family members, friends and caregivers began to add up. More than a decade and a half of SCI-life had



Claire, Ila and
proud papa Kenny
Salvini



taught me that it's better to be an open book than to try and hide the nitty-gritty details, but Claire wasn't as well versed in that PR strategy. Her being all hopped up on hormones didn't help matters either.

During a brief social media hiatus, she took up journaling and watercolor painting as creative outlets to help sort through the endless barrage of feelings. She also found support from other quad wives and girlfriends who had been through IVF, and she connected me with quad dads who had utilized sperm donors, which was a good reminder that fatherhood went far beyond the contribution of a single cell. "That was a game changer for me," says Claire, recognizing the tremendous value in sharing our up-and-down journey. "The more I shared, the more supported I felt."

SUCCESS! WE IMPLANT OUR BABY-SICLE

With our heads and hearts in a much better space, we decided to go for one more egg retrieval on May 17, the day before our first wedding anniversary. Another 22 eggs were harvested and 17 were mature enough to be inseminated with a vial of my successfully thawed sperm. The insemination process gave us seven viable zygotes as an anniversary present to go along with a quick detour to the ER for Claire who experienced minor internal bleeding from the procedure. Another six days on the teeter-totter, and we had two blastocysts to send off for genetic screening.

We were notified two weeks later that we had one viable female embryo ready to implant. We were elated, but not yet out of the woods. Because we only had the one, the doctors strongly suggested we do a mock transfer first, which is basically a full round of hormones to set up the transfer, followed by blood tests and a biopsy of the uterine wall to ensure we had the optimal environment for implantation. This pushed the timeline back even further and added an extra cost, but we didn't want to take any chances.

Finally, on Jan. 13, 2020, we implanted our little baby-sicle, and the clock started on the longest two weeks of our lives as we waited to see if she took. Of course, we cheated and bought a pregnancy test the night before, so the next day we weren't totally surprised by the news.



Claire and Kenny watch over Ila.

All that was left was 10 weeks of daily progesterone injections in Claire's backside to finish the first trimester. My lack of hand or arm function meant we needed help. Thankfully, a slew of family and friends volunteered, which made for more than a few awkward but hilarious moments. We knew our little girl's birth story was bordering on the absurd around the third or fourth time my burly,

230-pound neighbor came bursting through the door at 10:02 p.m. in a rush, apologizing profusely for being late and telling my wife to pull her pants down.

Once we cleared the 10-week mark, however, we were no longer considered a high-risk pregnancy, and were discharged back into the world with all the other eagerly expecting, scared shitless first-time parents ... just in time for the COVID-19 pandemic. Despite the global pandemic, the remainder of the pregnancy was fairly uneventful, save for the normal first-time parent anxieties and a few growth ultrasounds that should've tipped us off about our "little" girl's size. If anything, knowing the baby was over 12 pounds would have saved Claire 26 hours of fruitless labor, and my brief lapse in sanity when I first laid eyes on the adorable little chunk.

I guess we just needed that one last reminder that the path toward destiny and purpose are never pain-free. But isn't that how it goes with everything? If we really knew what it would take to reach our goals prior to beginning the journey, we might be scared away from even making the attempt. It's only when we look back that it all starts to make sense.

The in vitro process is a high-stakes, emotional pressure cooker that puts even the strongest relationships to the test. The steep financial burden, complete hijacking of hormonal systems and social schedules, and need for surgical procedures for one or both partners will put many existential and ethical questions on your doorstep. With a little luck and a lot of perseverance, you can make it through that gauntlet to witness one of the miracles of modern medicine, and life as a whole.

As we set out over the next 18 years to be this kid's tour guide of the world, we need to figure out how to explain the whole ordeal when she asks where babies come from. "When two people love each other *very much*, they assemble a team of doctors and scientists. ... And then we put you in the ice-box for six months. ... And then. ..."

MM

ETHOS



“The reduction in vibration has decreased my spasms,
giving me the energy I need to push further”

————— *Brittany H.* —————



THE THREE C'S OF MY FIRST YEAR OF MARRIAGE

BY ALI INGERSOLL

The definition of “in sickness and in health” in marriage vows needs to be considered more thoughtfully when one partner is disabled. The truth of it is not everyone is mentally equipped to handle all that comes with a disability for the long haul. As a C6 quad for nearly 10 years, my secret formula for navigating my first year of marriage boiled down to the 3C's — Compromise, Communication, and Compassion.

My husband, Aaron Watkins, and I met while I was undergoing surgery for a stage IV pressure sore. For the first six months of our relationship, I was healing in bed and we were only able to enjoy each other's conversation. I took the better part of that time to introduce him to the physical aspects of my care, which allowed us to solidify our bond to one another prior to moving forward in our relationship. In short, we built emotional intimacy and a strong connection before sex even played a role in our relationship.

This is where the 3 C's really come into play for us.

1. COMPROMISE

Before I jump into how the Compromise portion of the 3 C's guide us through our marriage, it's important I explain what



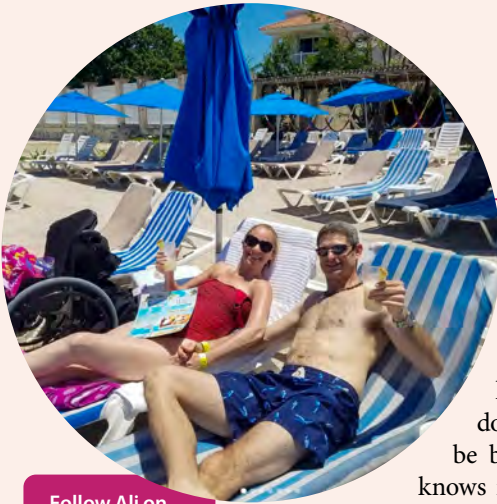
Incredible husband and wife time.

role Aaron plays in my day-to-day care. While I appreciate that some people arrange for their spouse to be their full-time caregiver for a variety of reasons, Aaron and I wanted firm boundaries to avoid blurring the line between caregiver and husband. We both want to maintain our marital relationship and not have him become my primary caregiver. I have caregivers five and a half days of the week, and Aaron handles my care the rest of the time.

When Aaron and I are on vacation or alone together for an extended period of time, we both have to compromise. I have a tendency to be nitpicky with respect to how I like things done with my care and have learned to sometimes let go of these preferences in order to enjoy quality time with him. In return, he has learned to be more patient. He doesn't always understand why I like things the way I do, but he respects my wishes for the most part. Of course we get in arguments, but what couple doesn't argue about something?

I like to rush through all of the caregiving stuff in order to get out and have fun, but Aaron challenges me to be mindful that even performing caregiving duties together is quality time.

Another care-related example of compromise is when Aaron gently tells me that just because I ask him to help me



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He's my husband, partner
and caregiver – how do we
make it work?

with so many things here and there, he doesn't have to always be bouncy about it. He knows it needs to get done and will do it, but I can't expect him to always jump to my every whim at a moment's notice as my caregivers are able to, unless it's medical in nature.

When paid caregivers are off the clock, they get to have their own time. It's different in marriage with a quadriplegic spouse who needs full-time care. We can't just step away from each other for a few hours when we get in a fight. We both have to cool off more quickly and sometimes hold our tongue because we are simply together all the time. This is hard and will probably always be hard.

However, when Aaron comes home to snuggle me in bed after an insanely long day, and wraps his arms around me and tells me he loves me, well, all of our problems seems to melt away in that moment. It's all worth it.

2. COMMUNICATION

I have a tendency to compartmentalize my feelings because, for my well-being, I need to ensure that the people responsible for my care maintain positivity. Oftentimes, I still feel like a burden when I have to ask people to help me physically. In our marriage I had to learn to communicate how I was feeling because Aaron gets frustrated with me when I do not talk to him, and I have the same complaint of him.

Taking in all the small
moments that we have to
spend with one another.



Early on, when Aaron wouldn't open up to me, I mistakenly believed it was because he was second-guessing his decision to marry a quadriplegic. But in reality, it was I who wasn't opening up about my feelings. I've become programmed to compartmentalize my feelings in order to keep everyone around me in a happy state of mind. This compartmentalization strategy does not work in a marriage.

Aaron often tells me that, while he can think of more fun things to do than help me get dressed or go to the bathroom, he fully accepted all that comes with me when we got married. I didn't understand this in the beginning because we didn't talk about it. I really just pushed my feelings to the side and he, in turn, just let it go. This was not healthy for either of us.

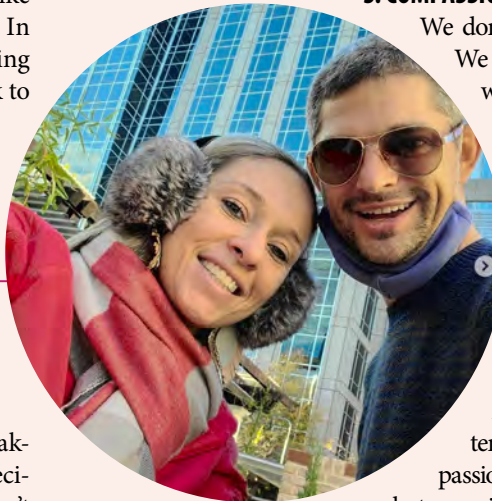
He is my partner for life and if we are going to make it work, we have to talk to one another. Caregivers will come and go, but if we both play our cards right, our relationship is forever. I do think it takes a special type of human to marry someone with a disability because for both sides there are added layers of adapting to a physically constricted-life.



3. COMPASSION

We don't always get along. We bicker, we fight, but we don't blow up at one another. I know there are moments we both want to, but we really can't afford to do that if we are going to make this marriage work in the long run. There needs to be an intense element of compassion in any marriage, but especially in one where a partner needs caregiving, for each party to understand the hardships the other one goes through.

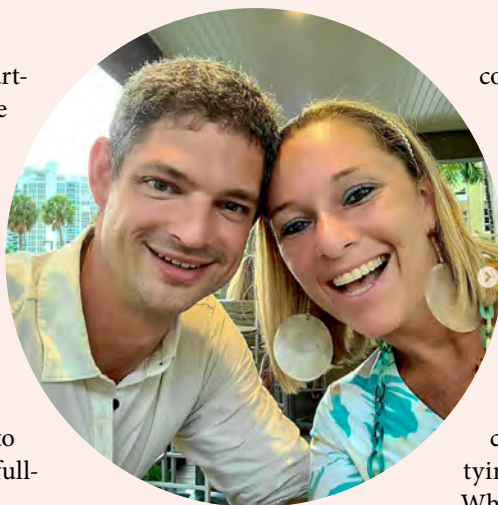
While being disabled may seem like the bigger hardship, the nondisabled person also compromises quite a lot to adapt



to the lifestyle of their disabled partner. For example, my severe nerve pain becomes so intense at the end of each day that I need utter kindness from my husband in order to survive my night sometimes. Aaron does that for me. In return, after he spends a long day driving around the state, I make sure he has meals in the fridge, his laundry is done, the house is clean, and finances are in order. I'm able to do this in addition to working a full-time job because I work from home.

Compassionate moments are everything.

Even when I am almost asleep, when Aaron gets home, he never fails to first give me a kiss, ask me about my day and tell me how much he loves me. No matter how sleepy I am, I muster up the strength to wake up to tell him how much I appreciate him. This ties into communication, but it's compassionate



communication to keep the emotional intimacy alive.

IN CONCLUSION ...

After a year of marriage, how have our expectations differed? Not much really because we are realists and had to have very matter-of-fact discussions about what it would take to make a marriage work, which I think is an essential ingredient for any couple to seriously consider about before tying the knot.

While my husband and I are fortunate to have the added benefit of a great sex life, sex usually dwindles

over time as the two of you grow old and wrinkle together. It is essential to make sure your bond is deeper than just a physical one.

So, if you don't work towards creating a solid base of emotional intimacy with each other, the ingredients to thrive in a long-term marriage, especially one with a

MM



Thank you to an incredible husband for taking amazing care of me and having the best time. I couldn't do this without you!

disabled partner, may not stand the test of time.



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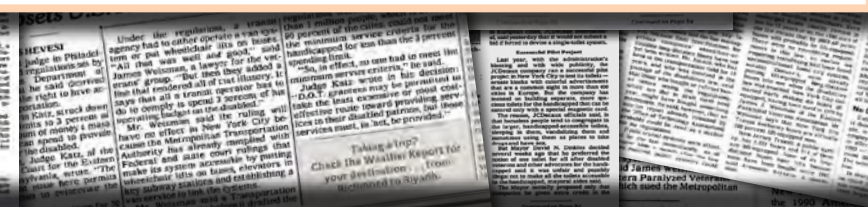
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JAMES WEISMAN

MAKING A CAREER OUT OF A PASSION

BY SETH MCBRIDE



James Weisman didn't want to fight about toilets. But in 1992 the Americans with Disabilities Act had just been passed, and New York City Mayor David Dirkins was insisting that the city install more than 100 outdoor restrooms across the city. The units were slick — self-cleaning after every use, with soap and warm water, and designed by a handsome Frenchman, Jean-Claude Decaux, who bequeathed them his handsome name. There was one problem with the JCDecaux toilets: they were totally inaccessible.

Weisman, then the legal counsel for the Eastern Paralyzed Veterans Association, informed the mayor's office that installing the inaccessible toilets would violate the ADA and he would seek an injunction to stop them. The mayor's office offered a compromise: for every JCDecaux toilet the city installed, they would build an accessible unit next to it, cleaned by an attendant and accessed by a special key card that the city, in its infinite generosity, would give out to deserving wheelchair users. Disability advocates balked at the separate but unequal solution — why couldn't all the toilets be accessible and used whether or not you had a key card?

New York media latched onto the fight, casting the toilets' inaccessibility as a virtue. Surely vagrants would find them too cramped for sleeping, but toilets big enough for a wheelchair to fit



in? Why not just give prostitutes and junkies free hotel rooms? One Manhattan resident — incensed by a New York magazine article titled "Toilet Wars," which painted Weisman and disability-rights campaigners as bladder-busting radicals — wrote Weisman a letter that finished with a line for the ages: "I hope you feel smug standing on the moral high ground while the rest of us stand in a puddle of urine."

Weisman looked up the guy who sent it and called him. "Hi, this is Jim

Weisman from Eastern Paralyzed Veterans Association, and I wanted to let you know that some nut is writing letters using your name." After a moment of dead silence, Weisman continued. "Look, I'm just kidding about the nut thing, but I don't think you understand what's going on."

Thirty years later — months after Weisman stepped down as the CEO of United Spinal Association, which EPVA changed its name to in 2004 — he still laughs at the ridiculousness of the whole episode. But he has no regrets about instigating the toilet wars. "I just couldn't let the city do it," he says. For him, disability rights have always been simple: disabled people should have the same rights and access as everyone else. When those in power aren't living up to their end of the bargain, you fight — even if it's about toilets.

A Whole New World

Weisman doesn't have a disability, and if it wasn't for the faulty memory of a Long Island grocery store manager, it's unlikely he would have spent the past 43 years of his life fighting for disability rights.

When Weisman was 16, he showed

ing more services. In recent years, the agency has been consolidating its medical centers and decreasing the number of its hospital beds. Representative Rick A. Lazio, the Long Island Republican who has said that he would challenge Mayor Rudolph W. Giuliani if he sought his party's Senate nomination next year, spoke briefly at the rally. Mr. Lazio said that his mother is a veteran and that his wife, Patricia, had worked as a nurse practitioner in two hospitals for veterans in New York.

"Staff reductions and unnecessary hospital closings are the problems that are most troubling," he said. "It's very clear that the President's budget is totally inadequate to meet the minimal needs of veterans."

Some veterans at the rally said they were concerned that the agency's medical centers seemed precariously understaffed, with medical assistants taking on tasks once reserved for doctors or nurses.

Others complained of arbitrary actions as

positions, trouble getting to see specialists, and an overriding fear that hospitals would be consolidated or closed.

Craig W. Sierra, 62, a Navy veteran who served on Graceland, said he was thrown against the bulkhead of a ship while on duty and is partly paralyzed.

He said he was concerned that the agency might close the Veterans Administration hospital in Cande Point, N.Y., near his home in Garden, N.Y., which would force him to travel either to Albany or New York City to get care. Either trip, he said, would be too expensive.

"They're dangling this as of doom over our heads and I'm tired of it," he said.

Paul J. Tobin, associate executive director of the Eastern Paralyzed Veterans Association, based in Queens, said other veterans lack adequate attention from medical personnel.

"There's simply not enough medical care to go around," he said. "Certainly, not everyone should be doing it."

York, Few Public Toilets

side a classic illustration of why everyone agrees that the city needs more public restrooms. People, tourists and homeless people, tourists and citizens. But for the plan to be effective, it will have to be a coalition of civic and business groups will have to be formed.

The issue most likely to be the most contentious is the plan to build new restrooms in the city's most crowded areas, such as Times Square and Grand Central Station.

For the time being, the city is planning to build new restrooms in the city's most crowded areas, such as Times Square and Grand Central Station.

Advertising for Access

As going up this week in New York City and 1,300 New York City residents are being encouraged to use as either full-time or part-time. The campaign is being run by the New York City Department of Transportation, which has 1,300 miles of subway and 1,300 miles of bus routes.

The campaign, which is being run by the New York City Department of Transportation, which has 1,300 miles of subway and 1,300 miles of bus routes.



Weisman's ability to forge relationships with elected officials, such as Ted Kennedy, greatly benefited the disability community.

in 1977. Weisman congratulated Hearne, "which was probably me pandering or patronizing," he says in hindsight.

"It's a piece of paper," Hearne replied. "Paper doesn't change your life."

They went to a bar down the street to talk. Hearne — who had to be carried up flights of stairs by his coworkers to get into his office at the federally-funded Legal Services Corporation — proceeded to educate Weisman on the realities of living as a disabled person in America.

A few months later, amidst a city hiring freeze, Weisman lost his promised job as an assistant district attorney and almost wound up working for a prison in California. Hearne convinced him to try to open an accessible legal services office in the city instead. At the time, 19 of New York City's 21 legal service centers, meant to serve low-income Americans who couldn't afford their own lawyers, were inaccessible. They needed funding for the new office, and Hearne met a guy who worked for Sen. Jacob Javits and got Weisman and Hearne an appointment.

As they drove to Javits' office, Hearne said to Weisman: "Watch this, the negative presumption at work."

"What's the negative presumption?" Weisman asked.

"We'll get to Javits' office and he'll talk to you because I'm in a wheelchair and he'll think I'm a moron. Then I'll speak up, and I'll only be as articulate as you are, but he'll feel like an idiot because he thought I was a moron, and he'll give us whatever we ask for."

Sure enough, the scene played out like it was scripted. They left the office with Javits supporting funding for their legal services center.

Shortly after they opened the new office, Frieda Zames, who'd attended Camp Jened of *Crip Camp* fame, convinced Weisman to attend an MTA hearing at which a number of advocates from Disabled in Action would be testifying. "When they get up to testify ...

the board of the MTA just gets up and walks away, as if they don't exist. They didn't even have the pretext of civility and manners. They were incredibly rude, talking to each other, getting coffee with their backs to the audience. One or two stayed at the table, but only so they could call the next speaker," Weisman says, his voice rising as he recounts the story. "I cannot tell you what this did to me. It got under my skin and stayed there a very long time. That kind of disregard for humans is unbelievable to me. I could not stand it."



James Weisman as a young attorney

A Career Advocating for Equality

When you talk with Weisman, and those who work with him, it's clear that his passion for disability rights is still as strong as ever. That passion has been built on his friendships within the community. Weisman met Terry Moakley, who worked in advocacy at EPVA, shortly after he opened up the



legal services office with Hearne.

A short time later, Weisman went to work with the governor's office on disability. Moakley attended a meeting where Weisman's boss chewed him out for siding with the disability community instead of the state of New York. After the scene, he followed Weisman to the men's room to gauge his interest in coming to work for EPVA. The next day, Jim Peters, the organization's executive director, called and offered him a job.

He's now been with the organization for 41 years, during which time he has seen it all. Some major wins, like the ADA, happened with head-spinning speed. Others, like the push to make New York City taxis accessible, took decades, only to have a world changed by ride sharing knock progress back at the eleventh hour.

After his hiring, he worked with Moakley on transportation issues. The two became close friends and would remain so until Moakley's death in 2014. Abby Ross, United Spinal's current COO, has worked closely with Weisman since he hired her in 2011. She thinks these relationships were one of the keys to Weisman's impact over the years. "He's considered part of the community in really intimate ways," she says. "He wasn't striving for fame or anything, it was all just part of him being himself with people he enjoyed and cared about, fighting for a cause he believes in."

Weisman's first big lawsuit came in 1979, when he sued the MTA over lack of wheelchair access across the city's public transportation system. Moakley and Peters were both plaintiffs in the lawsuit. It took six years, but in 1985 the city settled, agreeing to some key access provisions: installing lifts on all city buses, making key subway and commuter rail stations accessible and mandating

that all new stations would be accessible.

"He was really making a pathway for accessibility for people with disabilities before the ADA was ever really thought of," says Kleo King, who served under Weisman as the assistant general counsel for EPVA, ultimately serving the organization for 28 years before taking a job at the NYC Mayor's Office for People with Disabilities.

Weisman's negotiations with the city would form the basis for the transportation provisions for the Americans with Disabilities Act. "They always credit Sen. Tom Harkin for the ADA, which is true, but those transportation regulations are Jim's brainchild. They came from him sitting down in locked rooms, negotiating with the governor of New York for the settlement of the MTA lawsuit," says King.

As the ADA was being written, Weisman worked directly with lawmakers on the details of the law, as well as coordinating with the national disability organizers working to pass the law. "He was in D.C. a lot, he was at the table," says Helena Berger, who worked at the EPVA's advocacy divi-

AAPD

The American Association of People with Disabilities is a national, cross-disability civil rights organization that Paul Hearne helped found in 1995 to increase the political and economic power of people with disabilities. Weisman was on the board from its inception until 2020, including a term as board chair.

"Throughout my entire history with AAPD, the one person I knew I could count on was Jim. If I needed some advice, some help, no matter what it was, he was always there," says Helena Berger, who served as president and CEO of AAPD. "That is also part of his legacy — helping to build and grow AAPD."



James Weisman, Terry Moakley and Denise McQuade tirelessly advocated for accessible transportation.



Photo courtesy of New York Yankees



In 2019 the New York Yankees joined the Mayor's Office for People with Disabilities to celebrate Weisman's 40th year at United Spinal Association.

sion at the time and later went on to serve as the president of the American Association of People with Disabilities (see sidebar, page 31). “He was a very key player in those transportation provisions, and ultimately the passage of the ADA.”

In those pre- and immediate post-ADA years, fights over everything from employment discrimination, to stadium access, to curb cuts, often got contentious quickly. Americans often still saw disability as something to be cured rather than accommodated; the idea that people with disabilities should have the same civil rights as other minority groups was a bridge too far for some. Weisman remembers meeting with a city attorney, a Black man, who presented the city's offer for separate, accessible toilets. “I asked, ‘What if they had one like that just for Black people?’ He got up, walked out of his office, left me there by myself and never came back.”

Most of the time Weisman has a knack for making his point without pissing people off. He's boisterous, with a classic New York accent and a funny story for any situation — did

he ever tell you about the time that Adam Sandler stole a joke from him? — which makes it feel like he's been a lifelong friend, even if he only met you five minutes ago and just sued you. “He cares about what he does, and he cares about people, and I think that just comes through,” says Berger.

Broadening Reach

After the passage of the ADA, Weisman's role quickly expanded beyond lawsuits. Helena Berger says a big part of her post-ADA work at the advocacy division of the EPVA was to educate all the people who would be impacted by the law, from people with disabilities, to business owners, to state and local governments. Because of his personality, speaking skills and role in crafting the ADA, Weisman often spoke at educational conferences, helping people to understand the new law and the lives it affected. “Jim was always a part of that,” Berger says.

Of course, access lawsuits continued, but Weisman says they also found that now businesses were coming to EPVA, asking for help either before they got sued

or after they'd been flagged for an access violation. In 2005, Weisman helped set up Accessibility Services, an in-house consulting firm that provides accessible design expertise and has steadily grown to the point that last year they provided some 10,000 hours of service to 150 clients, from large hospital and university systems serving thousands of daily visitors, to local stores and restaurants. Often the mission has been not only to help with the details of code requirements but to help people understand why those codes exist in the first place.

“I've had people tell me, ‘I've gone out of my store and carried people in,’ and they think that absolves them of responsibility for all the people who don't want to be or wouldn't ask to be carried, and all the people who don't come to your business and who's quality of life is lessened by the inaccessibility,” says Weisman. “When people are done with us, not only have they removed barriers, they also understand the disability community better.”

Ross says that with everything Weisman does, he's able to understand the



United Spinal staff members appreciate Weisman — and his sense of humor — so much they had a bobblehead made in his likeness.

pointments, trouble setting to and an overriding fear that he would be considered as a danger to himself or others.

Craig W. Shera, 42, a Navy veteran who served in the Vietnam War, was diagnosed with post-traumatic stress disorder in 1995. He said he was concerned that he might lose his job at the New York City Department of Transportation, which would force him to move to a halfway house. He said he was concerned that he might lose his job at the New York City Department of Transportation, which would force him to move to a halfway house.

The "Archibute" said, "we're in a server in danger."

Advertising for... As going up this way cars and 1.5 Transportation Authority wheelchair users in one of a and two stops. The car Eastern Paralyzed Veterans, which has 1,000 in city.

The placards, signed "A Man Transient" and "A Progress," also say, "transit would benefit more. They don't directly a 'recreate' campaign in bus and ramped up into 10 stations scheduled for next in January a state sup

METRO DIGEST
NEW YORK CITY

Bids to Build Public Toilets Facing Limits
Dirkins Plan May End French Company's Role

By JAMES C. MCKINLEY Jr.
The subway administration and the City Council plan to build new public restrooms as a part of a \$1.2-billion transit expansion program, but a new report says the plan may end the role of a French company that has been a major force in building the city's transit system.

nuts and bolts of an issue and how they affect one another, as well as how the individual pieces relate to the overall goal of increasing access and community integration for people with SCI/D. "It's unbelievably valuable," she says. "He just brings people along with understanding how things will be impacted ... and how important it is, and they don't even have to make the calculation for themselves. He sells them on it."

Taking the Reins

Weisman's talent for seeing both the trees and the forest proved equally valuable when he was tapped to serve as CEO of United Spinal Association in 2015. Weisman had been handling legal counsel duties, along with a few other managerial roles, during a time of transition for the organization.

In 2011, United Spinal merged with the National Spinal Cord Injury Association and brought its extensive, countrywide chapter network into the fold. With the merger, United Spinal went from primarily serving veterans in the Northeast to becoming the largest SCI/D membership organization in the country. As you might expect, there were growing pains.

David Estrada, a wheelchair user who served as president of the Greater Boston Chapter of NSCIA, says that when the merger happened, there was "a bit of trepidation" about what life would be like under new leadership. "Jim was always able to explain things well and put people at ease ... he's been a great leader."

Under Weisman, United Spinal managed to get its finances in order while growing into its broader role — expanding its chapter network and

lobbying presence on Capitol Hill and in state capitols across the country and tending to the daily needs of thousands of members every year through its Resource Center. He also prioritized building relationships with Fortune 500 companies to ensure they understand the value and needs of people with SCI/D.

Weisman focused on the need to keep the organization running smoothly because he understood that every employee depended on it for their and

Over the years, Weisman and United Spinal have been drivers of concrete change to the built environment, but access has always been a means to an end. The end is a world where wheelchair users see themselves reflected in society and feel like their dreams — whatever they may be — are attainable. The more people with disabilities are visible and successful at the highest levels, whether it's in industry, sport, entertainment, advocacy or anywhere else, "the more it breeds the success of other people with disabilities," he says.

He got his wish. United Spinal's new CEO, Vincenzo Piscopo, is a wheelchair user who was working at Coca-Cola at the time of his injury. Rather than being given a retirement package and a few well wishes on the way out the door, Piscopo was encouraged to stay on with the company, to continue working, providing for his family and contributing to his community. Piscopo says that his story, along with all those of wheelchair users who

are able to live successful, fulfilling lives, are a testament "to the impact Jim has had, both on access and transportation across the country, but also to his unwavering passion and dedication to disability rights."

It's easy to get caught up in the daily battles to make disability a more normal, accepted part of society, but perhaps the most important lesson from Weisman's career is that while the details are important, you can't forget about the big picture. Continue to push disability rights forward and the path may not get any easier — but keep at it long enough and you'll be able to look back and see how far we've come. **MM**



Weisman marches with the United Spinal crew at a New York City Disability Pride march.

their family's livelihoods. "The temptation as CEO is to not think big — it's to balance the books, keep all the ducks in a row because you feel like that's your responsibility," he says. "At the same time, you have to be making autonomous vehicles accessible. You can't lose sight of the mission."

Onward

As Weisman prepared to hand over the CEO reins, he wanted no part of the search for his successor, but there was one criterion he felt was a must: Whoever was to lead United Spinal into the future needed to be a wheelchair user.

Nailed It, Failed It and Meh

How Disability is Depicted in Film and on Television

BY SYLVIA LONGMIRE

Wheelchair user
Daryl Mitchell
plays Patton
Plame on *NCIS:
New Orleans*.



I don't remember the first time I saw an actor in a wheelchair. This is probably because I didn't start using a mobility aid for my multiple sclerosis until 2011 and didn't become a full-time wheelchair user until 2014. After that, everything changed. It's like when you buy a new car in a particular color. All of a sudden you see that car absolutely everywhere. As an avid watcher of movies and television, I have now become hyperaware of disability representation in the media.

Historically, the inclusion of a wheelchair user or someone with another disability in a movie or TV show often centers around that person's disability. These forms of representation also frequently include the tired clichés of suffering, unhappiness or overcoming obstacles against all odds. It's rare to come across a disabled character in media today where their disability is completely incidental to the plot or where they're at least played by an actor with a similar disability.

Fortunately for us, every so often a film or television studio gets it right by casting an actor with a disability for a role that avoids cringy tropes. Unfortunately, many still don't. Following we share a few that have nailed it, failed it or are just meh.

Disability Representation in Film

Nailed it: One of these rarities recently came to pass with a Lifetime movie called *Christmas Ever After*. The star of the movie is Tony Award-winning singer and actor Ali Stroker, who is also a wheelchair user with an SCI. It's a typical Lifetime holiday romance with a happily-ever-after ending. What isn't typical at all is the fact that the main character's disability has absolutely nothing to do with the plot. In an interview with *People* magazine, Stroker said, "I wish I had seen stories like this. I wish I had seen myself represented in that narrative. It would have made such a difference in my life."

Failed it: Probably one of the most notorious recent examples of bad — if not downright horrible — disability representation is the 2016 film *Me Before You*. It's the story of a young woman (Emilia Clarke of *Game of Thrones*), who becomes a caregiver for a wealthy young banker (Sam Claflin from *The Hunger Games*). Not only is Claflin not a wheelchair user in real life, but his character decides to commit suicide when he realizes that life as a paralyzed wheelchair user is not worth living. It's hard to imagine a worse combination for an authentic representation of a disabled character.

Meh: *The Upside*, a 2017 remake of a 2011 French film called *The Intouchables*, depicts a completely incompetent and out-on-parole caregiver (Kevin Hart) attempting to assist with the physical needs of a wealthy quadriplegic (Bryan Cranston of *Breaking Bad*). As expected, Cranston took a lot of heat for playing a disabled character as a nondisabled actor. There are also many aspects of being significantly disabled of that are glossed over throughout the film. That being said, Cranston's character does effectively communicate the frustrations of having even the smallest freedoms taken away after an accident, and the difficulties of establishing romantic relationships. Personally, I thought the movie was really funny; but I also had to force myself not to focus too hard on the authenticity because I knew I would come away wanting.

Disability Representation in Television

Nailed It: One of the reasons I fell in love with Netflix's space exploration drama *Away* is the show's willingness to get into the nitty gritty of adjusting to life as a new wheelchair user. Although one of the main characters, Matt Logan, is played by a nondisabled actor (Josh Charles of *The Good Wife*) out of necessity, the show's creators and writers do an amazing job of getting the little details right, from physical rehabilitation to home adaptation, as well as the emotional trauma that starts piling up. Plus, the show's star, NASA Commander Emma Green, who is Logan's wife (played by Hilary Swank), sees psychologist Dr. Putney, played by real-life wheelchair user Michael Patrick Thornton.

Also in the Nailed It category is *NCIS: New Orleans*. There are so many variants of *NCIS* and *CSI* that it can be challenging to tell them apart. However, I'm particular to the New Orleans version because the character of Patton Plame (Daryl "Chill" Mitchell) is a wheelchair user both on and off the screen. He helps his team solve cases as the "computer guy," and the character is one of those unicorns where his disability is completely incidental and not the focus of an episode's plot.

Failed It: Could the 2020 drama series *Lincoln Rhyme: Hunt for the Bone Collector* be more terrible? First, the studio cast Russell Hornsby, a nondisabled guy, to play Rhyme, a quad. The wheelchair was wrong, the setup was wrong, his function was wrong, his body language was wrong — all of it was wrong. Even the concept, based on the novel *The Bone Collector* was wrong. The idea is that since he's a quadriplegic,

Rhyme needed a police partner, Amelia, to be his, "eyes, ears and legs as they tracked the cunning killer," as TVLine.com cringingly put it.

Meh: The long-running sitcom *Mom*, which is in its eighth year, has consistently picked up awards like the Emmy, People's Choice and Critics' Choice. The show follows a mother and daughter and their closest friends, all of whom are in Alcoholics Anonymous, which doesn't sound funny, but leads to hilarious antics as the women learn to not be as narcissistic or generally dysfunctional. One of the main characters, Bonnie (played by Allison Janney), falls in love with and marries a bar owner, Adam Janikowski, who uses a wheelchair. Adam's spinal cord injury doesn't have anything to do with the show and is depicted pretty well over all, but he's played by nondisabled actor William Fichtner. There aren't even any cheesy flashbacks of Fichtner walking to justify his taking the job from a real wheelchair user.

These selections are only a few examples of movies and TV shows featuring characters with disabilities, some much better than others. While there are many more I could have addressed, especially in television, actors with disabilities are still woefully underrepresented in Hollywood. While 20 per-



Ali Stroker's use of a wheelchair had nothing to do with the plot of *Christmas Ever After*, the Lifetime movie she starred in.

cent of the U.S. population has a disability, only 2 percent of characters do on screen. Furthermore, 95 percent of TV characters with disabilities are played by nondisabled actors, according to a 2017 study by the Ruderman Family Foundation.

There are more TV shows and original films on streaming services featuring people with real-life disabilities than ever before (hint: check out *Run* on Hulu). However, much work still needs to be done.

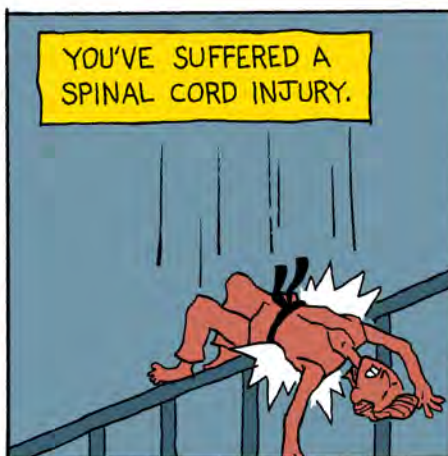
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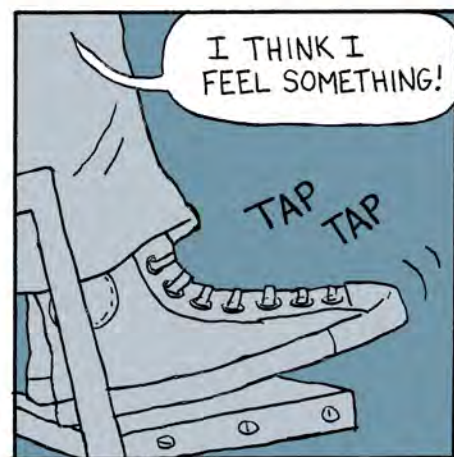
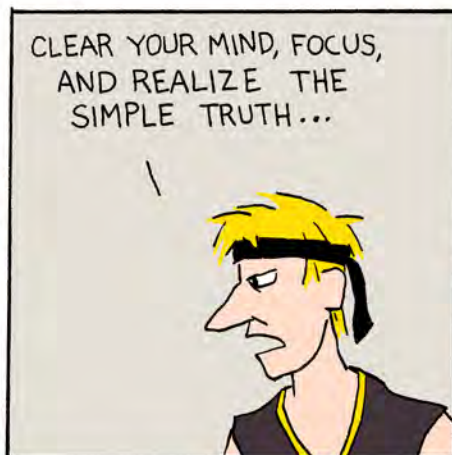
In season 3 of the Netflix hit *Cobra Kai*, everyone's favorite reformed karate instructor, Johnny Lawrence, shows off his unorthodox approach to rehab when high school crane-kicker Miguel Diaz sustains an SCI. Johnny tries motivating his prime student to heal by lighting his shoelaces on fire and dangling swimsuit magazines just out of his reach. Does it work? Of course it does, it's Hollywood! Mat Barton and Adam Cooper break down how Johnny and Miguel beat SCI.

HOW TO CURE YOUR SPINAL CORD INJURY

The Cobra Kai Way

By Mat Barton and Adam Cooper







PRODUCTS

By Michael Franz

TESTING ACTIVE HANDS' KITCHEN PACK DELUXE

In my many years as a quad, one of the most challenging things I have done is learn how to prepare and cook food. Admittedly, I am still not very good at it and do not do it as much as I should, but everybody needs to eat, after all. As with anything in the life of a quad, it is important to find the right tools and adaptations to be successful. Fortunately, Active Hands is here to help.

The Kitchen Pack Deluxe from Active Hands is a collection of 10 items designed for use by those with impaired hand function. The pack includes an anti-slip coaster and strips, a jar opener, a pair of knives, a palm peeler and several tools to help with opening boxes, cans, jars and bottles.

Approaching the pack as a C6 quad with no finger function and no triceps, I was unsure of how well its products would work for me. Most of the items I tested worked quite well, while a few did not work as I had hoped. I will start with the not-so-exciting but important anti-slip strips and coasters. They are made from a material similar to Dycem, which is used in many hospitals and rehabilitation facilities.

When using knives or working with bottles and cans full of liquid or food, it is good to know they will not slip and slide all over the place. The coaster is a good base for placing cans and similar items. It is also effective when used under plates or cutting boards. Likewise, the anti-slip strips can be wrapped around the handles of knives or any other utensil that may be needed in the kitchen. The pack also includes a non-slip jar opener. I do not

have the hand function to use it successfully, but it would work well for someone with some grip strength or the ability to exert enough downward pressure on a lid.

The two knives included in the Kitchen Pack Deluxe are perhaps the best adaptive knives I have ever used. The grip is at a 90-degree angle to the blade, which helps to reduce the risk of injury and to give users better leverage to cut. Even without finger function, I was able to use both knives without an adaptive gripping aid, but using a gripping aid does make it easier.

The blades on both knives are very sharp and cut efficiently. The bread knife has a serrated edge that is helpful when cutting with a sawing motion. The all-purpose knife is heavier than the bread knife, but the weight makes cutting much easier. When cutting cucumbers and peppers, I only needed to apply a slight amount of pressure and the weight of the knife was enough to glide effortlessly through.

Much like the knives, the palm peeler is a well-made and useful tool. The palm peeler is designed for the user to slip a finger through the ring on top of the device so that the blade is in the palm of the hand. Since I cannot straighten my fingers, I put my thumb through the ring and use the peeler with the side of my hand. The peeler requires little pressure to work and easily cuts through the skin of a cucumber.

While the knives and the peeler performed well and were relatively easy to use, the tools that are intended to help with opening different containers worked with varying degrees



of success. The best product of the bunch is the Nimble, which is essentially a tiny box cutter in a rubber sleeve that fits on the tip of a finger. I used it on my thumb and was able to cut paper, tape and thin cardboard. The only drawback is that the Nimble is designed to fit on a finger smaller than the thumb and sometimes falls off.

The 5-in-1 opener is a clever tool that works well overall, but not easily with my function. The opener is



designed to assist with soda cans, twist caps, crown caps, pull tabs, and vacuum sealed jars. It took a lot of practice, but I was eventually able to open soda cans and twist caps. The twist cap opener only fits on certain sizes of caps, however. The crown cap opener works like any other bottle opener, and likewise requires a little practice to get used to. Despite my best efforts, I was not able to open a vacuum-sealed jar or a can with a pull tab. Both tasks require a fair amount of strength and dexterity that I do not have.

The most disappointing products were the Automatic Bottle Opener and the One Touch Can Opener. The bottle opener slips over the top of a bottle and is supposed to pop the cap off when the user pushes down. It requires a lot of force for it to work successfully. I was not able to apply sufficient force, and my friend and sister both had to push very hard for it to



The Active Hands Kitchen Pack Deluxe makes a good starter pack for those seeking more independence, says Franz.

work. If less force were required it would be a cool gadget, but I think a regular bottle opener is more practical.

Much like the bottle opener, the One Touch Can Opener would be great if it worked as advertised. The can opener is

supposed to attach to the top of the can magnetically and open it with one touch of a button. What was supposed to be one touch ended up being many touches and an unopened can. After messing with it for about 10 minutes I was finally able to get a can open, but I still do not know what I did differently to make it work. There are certainly better automatic can openers available on the market.

Although the pack is not a complete set of equipment that one may need in the kitchen, it goes a long way in helping with performing basic tasks. It also is a good starter kit for those looking to gain more independence, or to get more involved with cooking and nutrition. With the exception of the automatic bottle and can openers,

I had a great experience with the other products. The Kitchen Pack Deluxe can be purchased at activehands.com for \$109.95 plus shipping, or each item can be purchased individually.



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IN THE MEDIA

By Teal Sherer

DIRECTORS IN CHAIRS

Before Jenni Gold says “action” on a dark sound stage in Los Angeles, she gives a crew member direction. “Yes, sir,” comes the response. “I appreciate the enthusiasm, but we apparently don’t have enough female directors,” says Gold, chuckling. “Yes, ma’am,” says the crew member, and everyone on set laughs.

Shot in 16 days, before the COVID-19 pandemic, *Aaah! Roach!!* is a horror-comedy film about a group of fraternity students that accidentally unleashes a plague of chemically-altered, man-eating cockroaches on campus. In addition to directing, Gold, who has muscular dystrophy and uses a power wheelchair, developed the story and is co-producing and editing it. “Roaches are the scariest thing ever,” she says. “I grew up in Miami, and no matter how clean our house was and how often the exterminator came to spray, I’d be brushing my teeth and one would pop out of nowhere and scare the bejeezus out of me.”

Gold went to film school at the University of Central Florida and is best known for the critically acclaimed documentary *CinemAbility: The Art of Inclusion* that explores the history of disability portrayals in film and television. Gold’s first feature film *Ready, Willing & Able* centers around a wheelchair-using former CIA agent. “I’ve had to create my own opportunities,” says Gold. “My goal has always been to be a director, but no one would hire me. I would get hired as a writer or editor. But to get hired as a director, I had to become a producer to fund projects to hire myself.”

There aren’t many directors with disabilities in Hollywood, and Gold is the

only wheelchair user that she knows of actively directing in the Directors Guild of America. “On the one hand, I am shocked by that, but on the other hand, I am not,” says Katherine Beattie, a writer and producer on CBS’s *NCIS: New Orleans*. “Our vision of directors is that they are up in the action, up at the camera, with the actors, and people can’t comprehend how someone who uses a chair would do that. But, as any of us who work on sets and use chairs know, it can be done.”

“Anywhere a camera dolly can go, I can go,” says Gold. “And if we’re shooting underwater, I will use video assist.” Gold feels that having a disability makes her a better director. “My entire life I have had to direct people to help me do things my way, and happily,” she says. “It has also made me a good problem solv-



Brian Balcom, above, began directing one-act plays in high school, shortly after his spinal cord injury. Below: Jenni Gold directs on the set of the horror-comedy film *Aaah! Roach!!*



er, which is key in filmmaking.”

Brian Balcom is a disabled Asian American theater director based in Chicago. Last March, the day after he opened Theater Wit’s production of *Teenage Dick*, the COVID-19 pandemic forced it to shut down. “The artistic director had foresight though and recorded a performance, which is how it survived,” says Balcom. From the comfort and safety of their own home, audiences watched online. “We had people tuning in from across the country, and the run got extended a few times. For a while, it was the only live theater going on.”

Part of Balcom’s job as a director is building relationships with theater companies he wants to work with. But things can become complicated when he discovers a rehearsal space isn’t wheelchair accessible. “Rehearsal rooms are potentially a minefield as far as access goes,” says Balcom. “They may be on a second floor of a building that doesn’t have an elevator, or it’s on the first floor, but the restrooms are in the basement. And how do you solve the problem? It can make you feel like you are creating a burden for the theater company.”

Balcom grew up in Minneapolis, Minnesota, and started out as an actor. “When I was 7, I was in a choir, and the choral director was the children’s director for the Ordway Theater and Minnesota Opera. She helped cast me in *South Pacific*, *La Boheme*, and *A Midsummer Night’s Dream*.” Balcom continued to act through middle school and after he sustained a spinal cord injury at 13. But in high school, he pivoted and started to direct one-act plays. “Back then, I had an awareness that the roles out there [for performers with disabilities] weren’t attractive. They were either after school special kind of things, or they were just there to forward the protagonists sense of empathy. And no one was taking the shots and casting disabled actors. If I was going to continue to pursue theater, I had to find another outlet.” Balcom applied for and was accepted to the four-year directing program at Carnegie Mellon University, and later got an MFA from DePaul University.

One of Balcom’s favorite things about directing is collaborating with actors and designers to create a world. “There is a moment in every production where I go into the theater for the first time and things are happening — things are being built, put up and painted. There’s this magical moment where I look at it and think, all of this is happening because of me, because of some idea in my head, because I pitched this

play, because I think this is a story that is important to share.”

Throughout the pandemic, Balcom has been directing play readings online and Gold directed a short film by capturing the actors through Zoom. *Aaah! Roach!* is expected to be out later this year. “A cockroach movie won’t solve the world’s problems,” says Gold, “but hopefully people will enjoy some creepy scares and a few laughs.”

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Meet New Member Santana Sen

Age 37, from Norwood, Massachusetts
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Why I joined United Spinal: I thought it would be helpful to connect with others experiencing similar lives.

What is the one disability-related product you couldn't live without? My power wheelchair. Without it, I would be confined to my home and bed. Instead, I am an independent, active member of my community.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be? I would change the stigmas associated with wheelchair usage. People who use wheelchairs are first and foremost people and should be treated as such.

Meet other members or join United Spinal at unitedspinal.org



photo by Malcolm McCurrah

NM LIVE *with Teal Sherer*

FEBRUARY'S GUEST: INVENTOR ANDREW SLORANCE

In this month's NM Live, I had the pleasure of chatting with United Kingdom-based innovator Andrew Slorance. He is developing the Phoenix i ultralightweight "smart wheelchair," which recently won the \$1 million Toyota Mobility Unlimited Challenge.

In our interview, Slorance shares details about the Phoenix i and next steps to get it ready for market. He also tells us what inspired him to become an inventor. Slorance's other products include the Carbon Black Wheelchair and Phoenix Instinct wheelchair-compatible travel bags. Meanwhile, six quick Qs for Andrew Slorance:

If you could have dinner with anyone, living or dead, who would it be? The entrepreneur in me wants to say Steve Jobs, but I would love to have dinner with my Mum, who passed nine years ago. She would have been so thrilled to see my business win the Mobility Unlimited Challenge.

What advice do you have for inventors who are starting out? Innovating a new product is properly hard, and you are going to lose your shirt quite a few times before you can make it work.

Have you noticed any differences between the U.K. and U.S. regarding disability and technology? I think Americans are faster adopters for new technology. They have more of a "let's do this attitude" versus the Brits, who are more reserved. Health insurance in America also seems to cover more for wheelchair users than the National Health Service does here.

Do you have any hobbies? I like to paint. It's my weekend therapy to get away from the stress of entrepreneur life.

What are you most looking forward to doing post-pandemic? Just to be able to go out and feel safe would great, but I can't wait to travel again.

Favorite place you've visited in the United States? I really love the atmosphere of Los Angeles, and the wheelchair accessibility of California is awesome.

Read more about the Phoenix i in this month's News Analysis on page 8. See NM Live at bit.ly/3980Fu4.

Andrew Slorance (left) helms the Phoenix i team as its main inventor.

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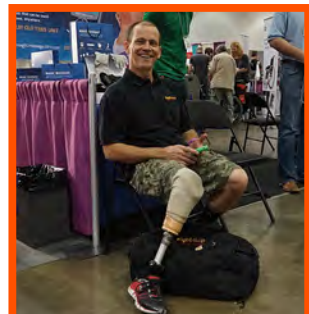
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