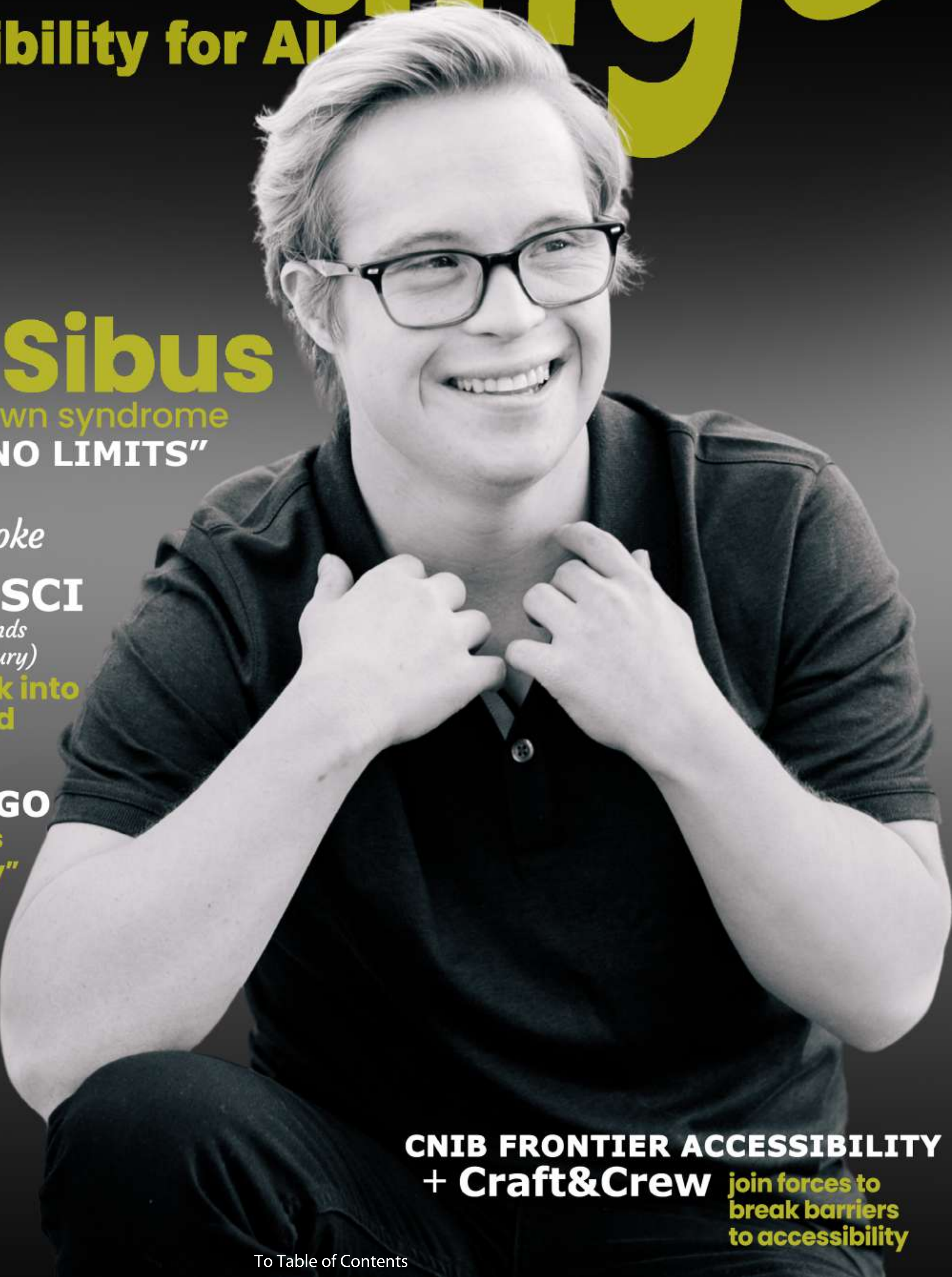
January 2022

mélange

Accessibility for All



Cole Sibus

Actor with Down syndrome

"WE HAVE NO LIMITS"

Elena & *Brooke*
Founders of
WAGS of SCI
(Wives & Girlfriends of Spinal Cord Injury)
gives us a peek into their world

JUDY SANGO
"Disability is NOT inability"

CNIB FRONTIER ACCESSIBILITY
+ Craft&Crew join forces to break barriers to accessibility

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January 24: Moebius Syndrome Awareness Day

January 31: World Leprosy Day

FEBRUARY

February 4: World Cancer Day

February 28: Rare Disease Day

MARCH

March 1: International Wheelchair Day

March 21 World Down Syndrome Day

January 4.

World Braille Day

Braille is named after its inventor in 19th century France, Louis Braille, who became blind at age 3.

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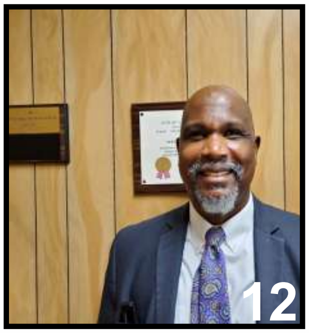
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Editor's Note

Fred J. Maahs, Jr.

Greetings!

Welcome to our January issue of Melange, Accessibility for All, magazine.

I think we can all agree that 2021 has been an interesting year for everyone around the world. We were all impacted by the Covid-19 virus and its variants in one way or another and perhaps the travel and tourism industry was impacted more than others. Yet, there were periods when travel increased, people began to attend sporting events, graduations, weddings, and more. Most were careful to participate in these events responsibly while others chose to put themselves and their neighbors, friends, and relatives at risk by not being responsible. The New Year is already presenting us with new challenges, and we remain hopeful for an end to Covid and then an end to wearing masks.

Melange Accessibility for All is excited about the coming year and all that it promises us! We will explore new places, introduce new products that help people with disabilities live more independently, and meet new people who are leaders, innovators, entrepreneurs, students, experts, newbies, and champions. We will highlight nonprofit organizations that serve and support people with disabilities as well as the staff that work each day to make a difference in the lives of so many. And, you may even see stories submitted from you, our readers.

And, we want to share some really great news with you. Melange Magazines will expand and offer a brand new digital magazine in March, 2022 – *Accessible Journeys*! In this new offering for our readers, we will share stories from all around the world about accessible travel destinations written and experienced by people with disabilities. In each issue, you will find personal, firsthand accounts of what each traveler experienced during their journey. It will be a resource for anyone of any ability who wants to take an accessible journey! We hope you enjoy it!

We will continue to make it all real, all relevant, and we certainly appreciate your thoughts. Let us know if you have a product you want us to try and write about or if you want to invite us to visit your city, country, resort, or place of interest so that we can write about it and share it with our audience. You can reach me fmaahs@readmelange.com.

Thank you for reading! Wishing you and yours a Happy and Healthy New Year!

Warm regards,

Fred J Maahs Jr

@FredMaahs - Twitter

Fred J. Maahs, Jr. is an internationally-renown disability and civil rights champion who believes in and advocates for the rights and access for all! A recognized leader and former corporate executive, he's also an International Keynote speaker, collaborator, and an international accessibility travel expert.

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ABLEISM:

Discriminating against someone because they are disabled.

According to the Ontario Human Rights Commission:

> "Ableism refers to attitudes in society that devalue and limit the potential of persons with disabilities.
>
> Ableism is…analogous to racism, sexism or ageism, [and] sees persons with disabilities as being less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others.
>
> Ableism may be conscious or unconscious, and may be embedded in institutions, systems or the broader culture of a society.
>
> Ableism can limit the opportunities of persons with disabilities and reduce their inclusion in the life of their communities."

Read the city of Toronto's advice about disability and inclusion

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We try to present information that is current and accurate, but errors can occur. If you've found an error in the magazine, please **email:** Fred Maahs, Jr.
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Mind of a Snail (Chloe Ziner _ Jessica Gabriel) credit Chloe Ziner

Realwheels Theatre

Since 2003, Realwheels Theatre has been doing what few other theatre companies have attempted: creating a performing arts scene that reflects the real world and all of its people. Under the direction of new Artistic Director Tomas Mureika, who has over 40 years of experience in theatre, film, television and music, Realwheels is undergoing a period of substantial growth and expansion. Mureika, who lives with Parkinson's, wants to "grow access, exposure and awareness of our community, grow our demographic, grow our pool of artists and grow our scope and scale of productions and workshops. If recent statistics show that 25% of Canadians self-identify as living with a disability, we at Realwheels strive to create an Artistic world on- and off- our stages and screens – proportionally reflecting this diversity of individuals so that our community not only sees itself in our productions, but feels comfortable being a part of our integrated and inclusive programming.

We want to produce unique multi-media projects unlike any experienced before and make them readily accessible to everyone...!" With its new proposed slate of projects ranging from inclusive and unique community-based workshop intensives to innovative professional productions, Realwheels' bold new directions builds upon the company's signature commitment to featuring artists of all fields with disability, offering truly immersive experiences to anyone who has a passion for all aspects of the performing arts.

Here are a few insights into what Realwheels Theatre has in store at present and in the very near future….

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Realwheels Acting Academy

The Realwheels Acting Academy is a free three-year performance training program open to those who self-identify with disability. Unlike most schools, its curriculum is unique in that it's tailored around each student's individual needs. Its innovation came from a desire to produce a safe space for everyone, a place where all people have representation on stages and screens. Created with cooperation with the arts industry, educational partners and counsel from Performers with Disabilities, the Academy's mission is to provide professional grade theatre and film training in order to help forward the need for systemic change and diversity in the artistic environment.

> **"A program like this cannot be understated"**
>
> *Ana Lanoway,* Interim Acting Academy Manager.

"[It's] created for and in collaboration with people with disabilities (PWD) and is more reflective of the needs of both the community and the arts sector."

Classes at the Academy aren't a typical Monday to Friday, morning until afternoon model; instead, students attend two days a week in class lengths that are more suitable to the disability experience in a space that has been adapted to accommodate their needs. The program focuses on Movement, Acting, and Voice from world-class instructors Camille Gingras, Shawn Macdonald, and Alison Matthews. Students can also look forward to summer discussion panels, which will see them learn about casting calls, finding a suitable agent and other practical insider knowledge that will help them find work in the film, stage and television industries. Launched in September 2021, the Acting Academy just completed its first module. But, as it turns out, being a pilot project, the Academy isn't just a developmental experience for students. Since the program is one of the first of its kind, there is a learning curve that the students, instructors, and management must constantly adapt to and change as they move throughout the three years.

Students have been encouraged to keep a journal of their experiences, both good and bad, which will then be analyzed by a specialist at the end of each term. This will help the Academy learn what works, what is lacking, and what needs to change. The students themselves are the driving force behind the Academy. "[They] are the real experts," Lanoway says. "Their experience will continue to grow the strength of this program."

Playwriting Circle Playwright-in-Residence

The annual Playwriting Circle workshop is just one of the programs Realwheels offers to playwrights who identify with a disability. It doesn't matter if they're a new writer or a professional who is just looking for additional feedback, this free 11-week program helps aspiring playwrights take their manuscript from dream to reality.

It's unfortunate, but playwrights with disabilities are generally absent from the artistic landscape. That's another systemic barrier that the Playwriting Circle wants to break down. "In performing arts in general, there is a desire to program plays that reflect the diversity of our society. In order to program works that depict a variety of lived experiences, we need to create them first," says Natasha Nadir, playwright and dramaturg for Realwheels Theatre. "This is an opportunity for artists who live with disability to go through an intensive writing program that supports their process."

As they explore the creative process, participants in the Circle receive ongoing input of their work from other students, as well as from Nadir. This feedback is meant to be constructive in nature to allow the playwright the room to let their script grow and evolve.

In December, as participants neared the end of the program, their plays took that next crucial step: having excerpts from their script performed in front of an audience in a staged reading Showcase of 10-minute scene excerpts, which was performed online again this year due to COVID restrictions. Each selection was read by professional actors – and for the first time this year, in front of a three-person jury, as well as an audience -- and from the work that was produced in the workshop, the jury selected one exceptional writer, who became Realwheels' Playwright-In-Residence.

The Playwright-in-Residence will receive a one-on-one intensive six-month residency with Nadir and a $3000 prize and Realwheels' operational supports to put towards helping their manuscript reach the next level. "The process of writing a play can only be strengthened by the support of a dramaturg, time, and resources. I am confident that whomever is awarded this residency will emerge from it with a very strong script that will find a place in Canadian theatre," says Nadir.

This is the first year that the position is being offered, an example of the type of growth and artist support that Tomas Mureika hopes to bring to Realwheels as the new Artistic Director. The idea for this new award stems from Mureika's own successful roots in playwrighting and wanting to encourage and reward original playwrighting and to develop new voices in Canadian theatre. The Playwriting Circle is open to all Canadian residents who live with a disability and is completely free of charge.

Wheel Voices: NO STRINGS ATTACHED

In March, Realwheels will be presenting a free six-day puppetry workshop. "Wheel Voices: NO STRINGS ATTACHED" will present puppetry concepts that will allow participants to experiment with different types of puppets in order to find the best character or embodiment that will help them tell their own personal story.

Participants will be introduced to hand puppets, shadow puppets, rod-operated puppets and an exo-skeleton that will require multiple people to operate.

Crispi at the puppet workshop with Pete and the Wall of puppets

The project is about letting those with a disability represent whatever or whomever they want through the creation and animation of what they design. During the workshop, the students are going to not only learn to create puppets that will their story, but will also learn how to manipulate them, make them work.

“This is a chance to work with a unique and diverse group of artists and learn from each other,” says Crispi Lord, Head Puppet Wrangler for Wide Open Children’s Theatre.

Crispi with the main character from Balloonacy (2019)

Frosty and Phillip J Yettington III from Frosty the Snowperson (2019)

In collaboration with Mind of a Snail and Wide-Open Children’s Theatre, this project hopes to do more than explore areas that have rarely been mined within the community, by taking the art of puppetry and making it more accessible to persons with disabilities. It also wants to recognize disability as a positive force and introduce new ways to promote storytelling that reflects that experience. Puppets have long been used in satirical ways or to reflect the day’s political climate, so why not use them as an extension or a symbol of a person’s body and its experiences? Because disability isn’t the same for everyone, stories will differ from person to person and will offer up a truly unique creation.

“Wheel Voices: NO STRINGS ATTACHED” is more than just representing and expressing living with disability in a new and exciting medium -- it’s also an opportunity to make connections with other artists and help grow participant’s circles in positive and inclusive ways. “Community connections make our art better and building bridges between communities makes our hearts bigger. I can't wait to listen, learn, share and guide as we explore storytelling, disability and puppetry,” says Lord.

Realwheels’ ultimate hope is to create a brand new community stage production for 2023 that has evolved from the workshop processes.

If you’d like more information about Realwheels Theatre along with its many programs and productions, please visit Realwheels.ca. You can also follow them on Facebook, Instagram, and Twitter.

In the next issue. . .

A new year means a new project – Take a special inside preview of Realwheels’ most ambitious multi-media professional production to date. It promises to be unlike anything you’ve experienced before! - Anglia Redding

REALWHEELS
THEATRE | PIVOTAL PERFORMANCES

Defining His Identity

Interview with Anil Lewis, Executive Director, Jernigan Institute at National Federation of the Blind

by St. Cloud Student Makayla Christen, B.S. in Psychology

Anil Lewis grew up in Atlanta, Georgia, as the third of four children in his household. Two of Anil's siblings became blind from retinitis pigmentosa, which, later at the age of 25, affected his sight. Lewis has learned to live by his motto, "Everyone has opinions, and everyone can have their perception of your worth, but you need to develop and understand your worth and uniqueness. You must define and advocate your own identity".

Lewis attended Georgia State University, where he received his Bachelor's in Business Administration Degree for Computer Information Systems. He then gained his Master's in Public Administration Degree for Public Policy. Lewis' experience in working towards and obtaining his degrees was a significant motivation to him. This motivation made him strive to work at a bank, nonprofit, or in an advocacy setting. Lewis became blind and later recognized that he could reclaim himself as an individual after a long and personally challenging experience. This experience led to him changing career paths and wanting to allow other individuals to reclaim their lives. The National Federation of the Blind, a civil rights organization for blind individuals, shaped his work today. The blend of academic training and personal experience created his drive for advocacy; in 2010, he worked as chairman of the disability committee at Georgia state. The position allowed Lewis to bring ability awareness to campus and make the campus more accessible to individuals such as himself and others who are within the disabilities community. Lewis is a very well-rounded and accomplished individual that found many meanings and outlooks within the various positions and advocacy roles he has held.

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Anil leads the crowd of blind and sighted members during a march for independence

Lewis first started his journey when he taught individuals to read braille and use assistive technologies. His natural love for technology and his past training and knowledge could be transferred into this field. Lewis later went further into the advocacy field and started advocacy in Georgia. After Lewis worked with the secretary of state, Georgia became the first state to provide accessible voting for blind individuals. He also worked to get access to 500 publications accessible for blind individuals. He worked diligently to impact educational programs that allowed students to get a quality education and adults to get proper and extensive training for work.

Lewis is currently the Executive Director for Blindness Initiatives for the National Federation of the Blind Jernigan Institute, located in Baltimore, Maryland. He coordinates outreach, marketing, and fundraising activities for the national nonprofit organization. He leads a team of "individuals responsible for creating, developing, implementing, and replicating innovative projects and programs throughout a nationwide network that works to positively affect the education, employment, and quality of life of all blind people". Lewis being the director of Advocacy and Policy for the National Federation of the Blind Jernigan Institute, allowed him to be the legislative leader of the National Federation of the Blind Jernigan Institute's efforts to repeal Section 14(c) of the Fair Labor Standards Act. This obsolete provision allows employers to pay workers with disabilities less than the federal minimum wage.

Anil chatting with BISM students (2009)

Lewis recognizes the difficulties many individuals in the disability community may face in the workforce. At the Jernigan Institute, he found it was easy to get the equipment and the support needed when completing any of his advocacy work or even the legislation work. The accommodations required were given and upheld to a high standard as well. He stated this created a false expectation that this is happening everywhere and is a model around. Lewis strives to generate this outlook and ideal for all in the community while being the Director of Advocacy and Policy. Lewis considers the ongoing struggle in the next ten years for the Jernigan Institute will be blind individuals getting access to braille, assistive technologies, teaching young children to use canes and be independent, and working towards blind adults having the same accessibility. The ten years hold something new and the technologies that will be created and instantly accessible to individuals without buying upgrades or creating shortcuts. It would also be individuals not having to buy a specific piece of technology to go about their daily lives; instead, the technology will not need routes to be accessible for use. One hope is that blind employees will not be treated and thought of as different but will be thought of and recognized as progressive entities in the workforce.

With this, Lewis wants people to know that it is nice to celebrate individuals' accomplishments and get some "skin in the game" no matter what level but to work still to push individuals to exceed their expectations and others. For the organization, it would be whatever way they can support the institute's work and be an active individual, or even a reactive voice for the struggle insidious in the disability community faces.

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Cole Sibus

An Actor with Down syndrome

“We have no limits”

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Meeting Cole Sibus for the first time, it will be immediately evident that he is an extrovert. His effervescent personality cascades throughout a conversation, humour seamlessly interwoven, eliciting frequent bouts of laughter from conversation partners. Witty, charming, fun-loving, daring, eager to try new things, compassionate and quite the conversationalist, Cole is a son, brother, athlete and actor. He also has Down syndrome, but this in no way defines him.

As an athlete, Cole enjoys a variety of sports including softball, swimming, tennis, and basketball.

His athleticism extended to his participation in the National Special Olympics as a member of the swim team, an experience which brings huge smiles to his face when recalling the experience. His was an amazing feat because he had to learn three swimming strokes in a short space of time, including the breast stroke and, he won gold! "It was wonderful," Cole said, "and I learned a lot of my strokes by watching YouTube videos."

Many may be familiar with the 24-year-old in his role as the young Ansel Parios, on the ABC TV show, Stumptown. In that role, he played the part of a shrewd, caring teenager with Down syndrome who was eager to be independent. He worked at a restaurant/bar run by a friend of his sister. Although she was understandably over-protective, Ansel managed to assert his independence and earned his sister's respect for his ability to make decisions for himself, one that included eventually moving out!

That role is indicative of Cole's real-life circumstances – he recently moved out of his family home and is enjoying his independence, in his own space away from the family, but with caring roommates who look out for him. "It feels different, "Cole shared, "but it's fun." He's often included in his roommates' social activities such as rock climbing and surfing among others. He regularly visits his parents but now has "his own place."

Although Stumptown was the most exciting of his acting career to date, having as a co-star, big-name actors Michael Ealy (Detective Hoffman), Colbie Smulders (Dex), Jake Johnson (Grey), Tantoo Cardinal (Sue Lynn), Adrian Martinez (Tookie) and Camryn Manheim (Lieutenant Cosgrove), Cole was already familiar with the world of acting prior to Stumptown, having starred in the 2017

reality TV show, Born this Way. This was a show about young adults with Down syndrome navigating their way through life. As he recounts how he got into acting, he laughs, "You'll love this story," he said. "My sister, Lauren, did home videos and my mom made her put me in her movies." Then I realized that I liked acting so I auditioned for Born this Way in 2017 and got the part; then in 2018, I auditioned for Spare Room, an independent film, and got the part, and then Stumptown!"

Cole describes his character, Ansel, as being "kind, sweet and smart" and he hopes people who watched the show will have learned this one fact about people with Down syndrome: "that we have no limits! We can do the same things typical people can do."

Cole's dream is to act in a family film with The Rock, Dwayne Johnson as his dad.

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With his parent's support and encouragement, Cole now has a real-life job working at a local restaurant – something he absolutely loves! He sets the table, gives the menu to diners and pours their coffee. "I really love it. I love seeing people every morning," he shared.

Cole encourages employers to be inclusive and to recognize that people with Down syndrome and other disabilities do have skills that can be used in the workplace.

Working out is one of his favourite pastimes and he has also recently started taking Jiu-Jitsu lessons. He has an active social life which includes hanging out with his sister, family, his roommates, and friends at church. Cole has a girlfriend, Teresa, who is a photographer and DJ, so times spent together are always fun-filled. They share many similar interests and, among other things, both enjoy boating, surfing, wake boarding, going to church and to the movies - their favourite movie is "I Still Believe".

Although Cole enjoys a full life, challenges still occasionally dot his path but he is undaunted.

Cole, with Teresa

He admits that one of the biggest hurdles he's encountered so far was "having to learn how to memorize my lines and get into my character when acting." But he mastered it, with "practice, practice, practice," he said with pride.

As a confident young man, Cole gives sound advice: "Be yourself. Don't try to be someone you are not. I don't want to be that other person - I want to be my own person," he declares.

"But," he says reflectively with a twinkle in his eye, "unless I get to be the next James Bond. Then I'll be *that* person!"

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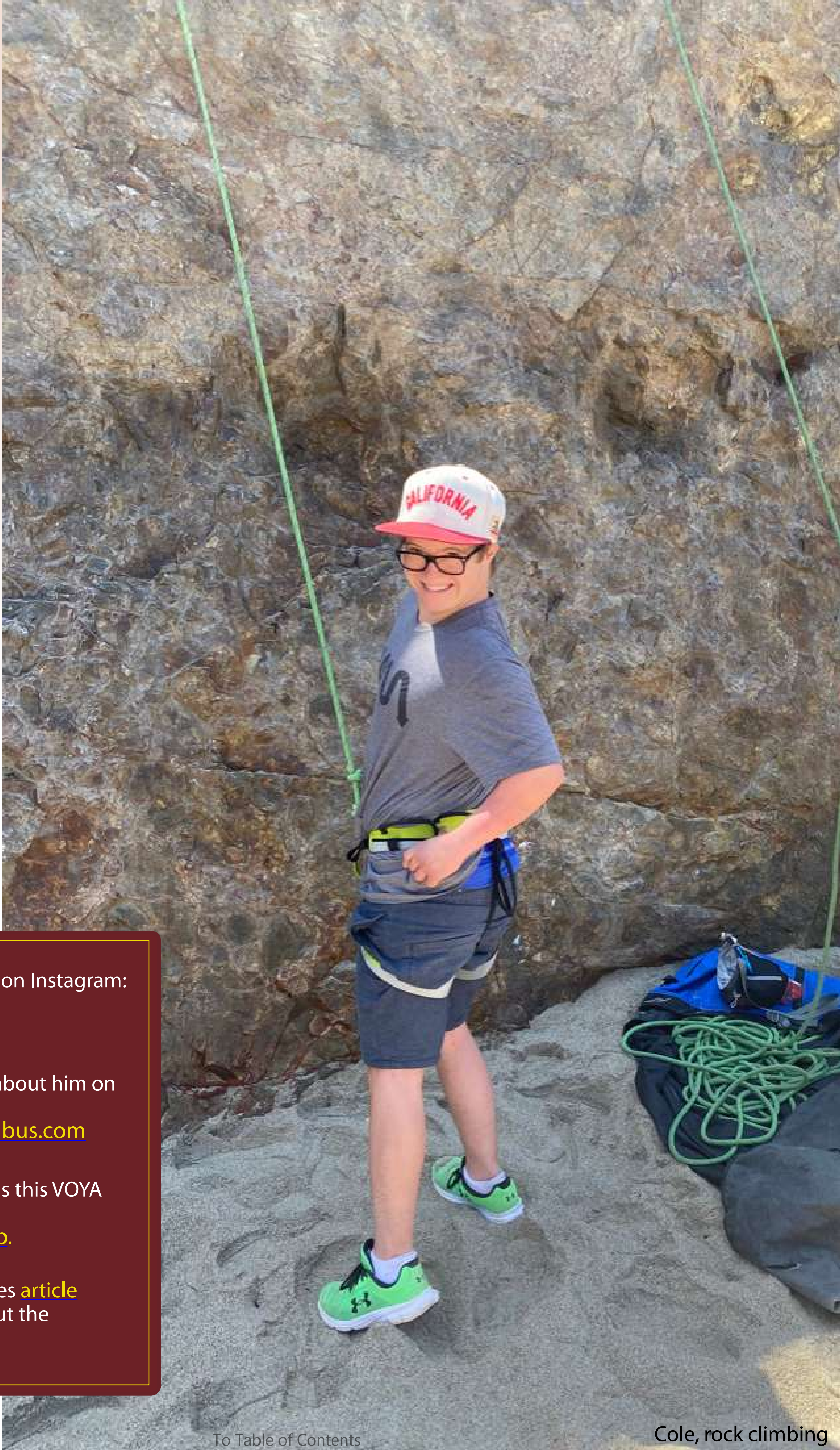

Follow Cole on Instagram:

Read more about him on his website: www.colesibus.com

Watch Cole is this VOYA commercial: Growing Up.

Read a Forbes article written about the commercial.

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Cole, rock climbing

Retired attorney, Roger Chard talks about a life of Grit, determination, self-reliance AND excellence

Part 1 of 2

My father was totally blind and was educated at the Michigan School for the Blind. He earned bachelors and masters degrees in music from Michigan State University and the University of Michigan. He taught at the Michigan School for the Blind, primarily as music director, from 1939 to 1977. I was young enough when I went blind that I do not recall seeing.

Other than part time attendance at a public school in my junior and senior years, I was educated at the Michigan School for the Blind before mandatory special education, so I was not mainstreamed (as once known), or "included" as now known. I earned a bachelor's degree in social science from Michigan State University in 1969 and a law degree from the University of Michigan in 1972. I practiced law in Ann Arbor, Michigan for thirty-eight years and was the only blind attorney in Ann Arbor for that entire time. With the indispensable reading assistance of my mother, college undergraduates, and others, I was formally educated and practiced law for fifteen years before software and adaptive devices became available that converted print to speech, that let me echo my type strokes and read what I was typing, let me accelerate speech without increasing its pitch, and that allowed me access to virtually every local and online mode of communication available to anyone else.

My father lost his sight from retinoblastoma, and so did I. He and my mother came from Michigan Upper Peninsula mining country, and they instilled in me redeeming grit, determination, and self-reliance that, to this day, one finds in abundance in the UP. They grew up during the Great Depression, and they proudly exhibited the style of that era - making one's way with limited resources, with few if any second chances, with tough mindedness, by asking for and giving no quarter. They wanted me to learn as best I could, to be every bit the student and person that my sighted peers were, to be involved in a variety of activities outside of school, and to do everything well in which I was involved. They wanted me to live a well-rounded life and their exacting, though not unreasonably demanding, personalities made that happen.

I entered kindergarten at four, and my father already had taught me a lot of Braille. I began piano lessons at age five. I went to summer school in second grade to learn to type. When I later typed assignments and made mistakes, type-overs were not acceptable, retyping the assignment was. That was a hallmark of my dad when I played French horn in his band. He was a driller: "We'll play it until we get it right." I learn and practice music that way to this very day and carried some of that approach into practicing law.

My parents encouraged me to join the School for the Blind's first debate team, but the coach left after two years and the team disbanded. A coach at one of Lansing's public high schools asked me to debate for him, and my parents arranged for me to attend both schools and

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debate for the public school, with which school I was a varsity member of the 1965 Michigan State Championship team.

While growing up, I walked all over Lansing with my dad, spent time climbing bridges, walking railroad tracks and narrow, shaky, unguarded catwalks, riding switch engines, doing much that now is prohibited, but also learning how to travel independently. It was assumed that I would go to college, but to which one was not clear until Michigan State University recruited me to attend school and debate there. But I had to choose a major among music, teaching, or pre-law.

Twelve years of piano study, seven years of French horn study, playing French horn


Roger and Maurita in Antarctica


Roger in Antarctica

and tuba in my father's school for the blind concert and marching band (one of only three such marching bands in the U.S.), singing in high school chorus all pointed me to music, but debating, interest in things political, the chance to teach or go to law school prevailed.

I majored in history, sociology, and political science at MSU, sang with the men's glee club, debated there for four years, was named national college speaker of the year in 1969, traveled extensively with the debate team and glee club, loved every minute of my four college years, and went on to Michigan for law school. My dad was a band director who always had wanted to sing, and at his urging, I took my first private voice lesson after graduating from college.


Roger Chard and Maurita Holland.
Read a related story here

Blindness was not a permitted excuse to do something less well than I could.

My father firmly believed that he and I must do things twice as well as our sighted counterparts to be regarded as their equal. I worked under the pressure of academic, piano, French horn, debate, and choral performance, and those pressures, the lessons from my parents of how to approach everything I undertook, and my own competitive nature got me through growing up and gave me a tough-minded foundation for moving into and through the workaday world, made me eager to pursue vocal study and performance, and to start downhill skiing after age forty.

Roger Chard Parry Peak

I got married in the summer before entering law school, remained married until 2004, and became the father of two boys, Brendan and Devin, one of whom went into business for himself, the other of whom became a police officer with the Las Vegas Police Department.

While growing up, I . . . .spent time climbing bridges, walking railroad tracks and narrow, shaky, unguarded catwalks, riding switch engines, doing much that now is prohibited, but also learning how to travel independently

Roger biking

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Challenges encountered as a blind lawyer

(1) From the start of college, the toughest thing was keeping up. In law school, case books, as law school textbooks are known, constantly change as statutes, case law, administrative rules and regulations change. Even if a case book had been recorded (a rare thing when I went to law school), it almost certainly would not be the edition used in a class I would be taking. Professors naturally insisted on using the most up to date case books and also passed out many reprints of recently published case opinions, new or recently revised statutes, rules, and regulations, along with new articles discussing these materials. I relied on my mother and other readers to read to me in person or to record the materials I had to read for college, law school, and the first fifteen years of law practice, but there was no way I could get a class assignment and get it recorded or read to me in time to be ready every day for class.

Reading quantities and deadlines sometimes were a challenge in practicing law, too. My reading speed was limited to the pace of the given reader, and if I wanted to increase the speed of recorded material, I had to turn up the speed of the tape recorder and put up with the much higher pitch of the sound; it was a bit like listening to Donald Duck. I borrowed $25,000, computerized in 1988 and got the benefit of digital reading from screen reader software which read everything that came to the computer screen and from scanners that allowed me to put a print document on the scanner lens, push a button, and have the print converted to speech. Other controls in these programs and on these machines let me increase speed and volume as I chose (default reading speed was 400-425 words per minute), without increasing pitch. I could have my type strokes echoed so that I always knew what I had just typed and where I was in a document, I could word process, convert documents to Braille, Braille them out with a Braille printer, and I was able to get online like anyone else (having learned to type at age eight was valuable). This also meant I could cut back on hiring readers.

(2) A second challenge was being comfortable with an ever-expanding world of photography and other technologies. I had to be sure that people on whom I relied to describe things to me were competent to the level I could trust. I could not risk being under prepared and/or uncomfortable in working with exhibits that were or might be part of a court hearing or trial. That meant being sure to have someone I trusted available to provide sighted assistance in situations where I thought it might be needed. Like life in general, anticipation was the key to addressing these concerns in law practice. Similarly, I could not afford to have clients be wary of my ability to work with items that were or might become an important part of their proceedings. An attorney dealing with any critical element of a presentation--photographs, physical equipment, workings of a process, the way in which a structure is arranged - must learn about that element to the maximum level of understanding, and sometimes lack of sight made learning a little slower going than if I had been sighted.

(3) A third challenge was relating to people when I could not see them - clients, jurors, witnesses, opposition attorneys, judges, court personnel. But everyone has his or her own way of assessing people, and that simply was something I had to deal with in ways that let me compensate for not seeing. There are work-arounds on which I have relied throughout my life for this compensation. Listening is an enormous key. People pay very little attention to their own voices, for example, and one who pays a lot of attention to voices can acquire a lot of information about a person he or she doesn't even realize they are divulging. Are there cues I might have noticed had I been able to see someone, of course, but I never have seen, I always have had to make up for visual cues that may not be known to me, and I have not beat myself up over what I cannot control, might be missing, to the possible exclusion of what I can control. Reading available background information was very important, too.

(4) A fourth challenge was understanding the physical layout of a space. It might have been where an important object was located and how it operated within the location. It might have been a new courtroom and how I could operate within it. Taking the time to visit the location and ask questions in advance, taking time to visit the courtroom and walk around in it before appearing for a hearing or a trial were critical to being prepared and being comfortable. Early on I realized preparation was absolutely crucial and I never wanted anyone to think I was not prepared because of being blind. Of course, this also has been true for undertakings outside law practice--music performances, theatrical appearances, presentations of any type.

I have been blind all my life, so I never really thought about approaching law practice in a manner distinctly different than I thought about doing anything else.

I identified what had to be done and then set about doing it in the best way the tools I had would allow. I have been blessed with a good memory, I had a good command of Braille, I sought to be as independent as possible in mastering what I could do without the assistance of others, I insisted on surrounding myself with the best quality support I could obtain, and I always sought to develop and cultivate good networking. Memory was key to smoothly functioning. I always have carried a lot in my head and not counted on just being able to find something or look it up when needed. Many people close a file folder, and the matter is out of sight, out of mind. I never have been able to operate that way. Lots of things come up repeatedly in the practice of law that I always wanted to have at my mental fingertips, looking up was just to make sure. Braille was how I kept notes for years, using the slate and stylus and Perkins Braillers, and even after not having to do that exclusively, I still used Braille heavily. It was necessary for taking notes in court and for setting down arguments I took with me to court, and Braille, after all, was how I learned to read and spell. Reading by ear was not so common when I was growing up as it has become. The huge decline of Braille use is something I regret.

Independence is something I always have treasured: the ability to come and go (I use a white cane), to do things around the house or office, to perform as many tasks as possible that my sighted counterparts perform.

The more things one can do with facility, despite some sort of ability challenge, the more likely a disability will be forgotten and that one will be regarded as just another competent contractor, teacher, staff member, home maker, salesman, stenographer, social worker, machine shop employee, vending stand operator, lawyer, etc.; and the less

likely one will be thought of as an amazing exception, as some sort of miracle or miracle worker. Independence helps maintain resolve, high levels of concentration, strong/tough mindedness.

High quality support is crucial to any lawyer. Whether it is law clerks, paralegals, or secretaries, one's own efforts are enhanced by quality support. In the case of being a blind lawyer, it is critical to have people whose attention to detail is above average, for the reality is that being unable to see eliminates one opportunity for catching mistakes--a document mistake, a personal appearance problem, something that a client might see on the desk that shouldn't be seen, and so forth. There is more to practicing law than just making oral arguments in court or written arguments in a brief.

Developing and cultivating good networks is indispensable. This is true, whether sighted or blind. It is an important part of how one is regarded, as well. I always wanted to be able to constructively draw from and contribute to any network with which I was associated--a judicial committee, a research group, a legal writing group, an organization of entity directors. I did not want to be thought of as unduly reliant because of my blindness. This is another aspect of what I mentioned above, of being a member of a group without drawing extra special notice to a so-called disability. None of this has anything to do with trying to pretend not to be blind, I never have tried to hide my disability, but it concerned fitting into any facet of work or non-work as seamlessly as possible, fitting in without drawing attention to oneself unnecessarily. I never have regarded myself as a model for how to live blind, yet a person with a disability is inescapably an exhibit, a model of how to operate with that disability, like it or not.

In the very first essay of the New York Times series on disabilities, Rosemarie Garland-Thomson makes this important point: "A person without a disability may recognize someone using a wheelchair, a guide dog or a prosthetic limb, or someone with Down syndrome, but most don't conceptualize these people as having a shared social identity and a political status. 'They' merely seem to be people to whom something unfortunate has happened, for whom something has gone terribly wrong. The one thing most people do know about being disabled is that they don't want to be that."

Yet, disability is everywhere once you start noticing it. A simple awareness of who we are sharing our public spaces with can be revelatory. Wheelchair users or people with walkers, hearing aids, canes, service animals, prosthetic limbs or breathing devices may seem to appear out of nowhere, when they were in fact there all the time.

"The more we with disabilities can model the point that we are able to participate fully in society, including the workaday world, the more likely it will be that able bodied people will be comfortable in associating with someone who has a disability and the less likely it will be that disabilities will be regarded with fear and apprehension."

. . . to be continued in the next issue

Roger in Australia

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"Disability is not inability"

~ Judy Sango ~

21-year-old Judy Sango has big dreams. One of her dreams is to become a judge.

Judy was born with Arthrogryposis, a condition that affects the joints. With frequent pain in her knees resulting in her having to use a wheelchair to get around most of the time, life has been challenging, but the prodigious support of family and the community has helped significantly.

Growing up in the small village of Chance on the Caribbean island of Dominica, Judy was shy, and during her time in primary and secondary school, she was bullied. This, however, increased her resolve to overcome whatever challenges may come her way. She recalls her fellow students expecting her to take a back seat at school events because of her disability, but over time, she decided to step up and use her voice.

Today, Judy oozes confidence. As President of Caribbean Youth with Disabilities Connections, she conducts the group's Sunday evening meetings with polite precision.

Being in this role gives her the opportunity to use her leadership skills which she developed in high school. She once enjoyed a tenure as Environmental Science Club Treasurer, functioned exceptionally well as a trained peer counsellor and was a natural leader at school assemblies. She was and still is also very active in her church. Judy reveals that having a "disability has been a blessing in disguise. "My focus would not have been the same if I did not have a disability," she shared. "I am exploring areas of life that I may not have done. I am more compassionate and filled with love for humankind."

Judy admits that her life has not been easy, and one of the main hurdles she dealt with was her own personal view of herself. For many years, she struggled with self-image. Although outwardly she seemed to be in control, inwardly, turmoil raged as she continued to battle with the person the mirror told her was not suitable. That changed in 2015, when she was recognized by the National Youth Council of Dominica and granted the Esteemed Challenge Award. Gradual change started at that point and now she is on a quest to confidently achieve her lifelong dreams.

From the tender age of three, she knew she wanted to be a judge, and now at twenty-one she declares, "nothing will stand in my way." Each day brings her one step closer to achieving her goal, and although this journey consists of many, many years along a path of numerous uncertainties, Judy remains resolute. "I will get there! Education allows people to escape from hardship," she said, "and the only real obstacle that stands between me and my goal can be myself and no one else." With two more years left in college, Judy has her eyes set on attending the University of the West Indies, Cave Hill Campus in Barbados to pursue her law degree. This is the next step for her. She is not yet sure how, but believes that she will find a way.

While a career in the legal field remains at the forefront of her mind, she harbours an interest in accounting. App Development comes a close third on her list – being an entrepreneur is a pleasant thought. Intertwined amidst all of her grandiose plans is the one she holds dear, that is, to become a recognized disability rights advocate in the Caribbean. Her aptitude for public speaking lends itself well to this and she is keen on one day helping people with disabilities to reach their potential.

As plans for a future of great possibilities are being crafted, the first on the list will soon be realized. Judy is on the cusp of becoming a children's author. She reminds people with disabilities:

> **"Education is important.**
>
> **At times, things may be difficult, but do not be hesitant to pursue your passion."**

Defending our rights in many roles

Interview with Andrés Gallegos
Chairman of the National Council on Disability

Written by St. Cloud State Student, Taylor Mulcahy, B.A. in Psychology

Four years ago, Andrés Gallegos participated in the Pikes Peak Challenge in Colorado Springs, Colorado. He rolled up Pikes Peak Mountain in his manual wheelchair from the base at 7,300 feet above elevation to the mountain summit at 14,100 feet above elevation, which took him just over six hours. In doing so, he raised over $7,000 for the Brain Injury Alliance of Colorado.

Gallegos did not initially intend to become a fierce advocate (professionally and personally). After graduation, the Chicago native enlisted in the United States Air Force and spent 14 years in active duty until being honorably discharged. He worked to obtain his undergraduate business management degree from the University of Southern Mississippi. He then went on to attend law school at St. Louis University, working in their evening program for the first year until he separated from the Air Force to finish law school full-time. Post-completion of his law degree, Gallegos moved back to Chicago. However, Gallegos sustained a spinal cord injury in a horrific automobile accident in November 1996, resulting in quadriplegia. At the time of the accident, he was only three years into his already successful legal career, working as an associate attorney and focusing his talents on corporate and international trade law. After spending five months in the Rehabilitation Institute of Chicago, Gallegos returned to work as an associate attorney, having to reinvent how he did things. He was still working on corporate and international trade matters, and began working with healthcare clients, and eventually made partner at that firm and was with them for about 10 more years.

Gallegos then left his firm and started working at Robbins, Salomon & Patt after merger discussions between the two firms fizzled. It was at Robbins, Salomon & Patt that he started focusing on addressing the needs of people with disabilities – Gallegos did not embrace his disability until about 10 years after his accident, and began advocating for himself when he truly realized the depth of the barriers he and his community faced. It was this realization that lead Gallegos' practice to transition from corporate and international trade to healthcare matters and disability rights and advocacy. This transition was fully supported by Robbins, Salomon & Patt, and led to the founding of the firm's disability rights practice, which is now a national practice with its main focus of addressing inaccessible healthcare for people across all categories of disabilities throughout the country.

Under Robbins, Salomon & Patt's new disability rights practice, Gallegos has achieved several stunning accomplishments that helped to change how disabled individuals access healthcare services. Their first case was class action lawsuits against the seven leading retail providers of eye examination services – LensCrafters, Pearle Vision, America's Best, For Eyes, Costco, Sears Optical, and Target Optical – to make their examination services accessible to people with mobility disabilities who use mobility devices and cannot independently transfer.

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Gallegos pointed out that for those who are physically disabled–if they cannot independently transfer from their wheelchairs onto exam chairs, an optometrist or ophthalmologist would either refuse to provide the examination or conduct the examination using a manual method that is not as effective or thorough as using modern optometry equipment. People who are physically disabled confront that same issue when needing dental care. If the person cannot independently transfer onto a dental examination chair, they would either be turned away or the dentist would complete a cleaning or treatment with the individual remaining in their wheelchair - an extremely uncomfortable and painful experience, particularly for the vast majority of people with physical disabilities who utilize wheelchairs that do not tilt or recline. Unfortunately, these concerns are rarely thought about by able-bodied persons.

Not only are these barriers leading to lower levels of care, but they also directly impact the health and well-being of the disabled community – persons with disabilities are twice as likely to be obese, and are at higher risk for unmet prescription needs and untreated dental issues.

Gallegos and his partners prevailed in each of those cases and the settlements required those providers to utilize rollers underneath the examination chair to facilitate moving it out of the way so that persons utilizing wheelchairs can position them in place. All of the eye examination equipment needed for a thorough examination is now placed on movable height adjustable tables or equipment stands for them to use. Additionally, Gallegos and his partners addressed the same issue at national dental clinics, specifically Dental Works and Aspen Dental, who were either dissuading people with mobility disabilities from obtaining dental care because they had no manner by which to transfer them out of their wheelchairs on to the examination chair; or were treating them while they remained in their wheelchairs. Gallegos negotiated settlements, requiring them to install overhead lift equipment for Aspen Dental, and Dental Works acquired lift and transfer equipment to use for those who cannot independently transfer onto the examination chair.


Andres with his grandchildren

With this significant success, Gallegos notes, “We have addressed physical accessibility for health care services with a number of healthcare systems in Illinois and in other states, requiring significant financial investments to make patient rooms accessible for patients with disabilities who utilize mobility devices; ensuring healthcare systems can safely transfer us from our mobility devices on to examination tables and diagnostic and imaging equipment when clinically necessary; and have addressed communication access issues for people who are deaf, ensuring healthcare providers provide them with appropriate auxiliary aids and services to achieve effective communication.”

Gallegos and his team are now finalizing a settlement with a municipality in central Illinois on behalf of people with mobility disabilities who live in that region to improve sidewalks and curb cuts throughout their city, which are now unsafe or nonexistent. Furthermore, Gallegos discusses that one of the biggest misperceptions of people with disabilities is that they have a low quality of life– this belief has deadly consequences in the healthcare space, which society saw play out during the height of pandemic when people with disabilities were being refused treatment for COVID-19 because of physicians' perceptions that disabled individuals had a low quality of life and therefore were not worthy of treatment, and were deprioritized for vaccinations.

This misperception can be changed, however– Gallegos explains that, "We need to have greater visibility and greater participation on the boards and in C-suites of healthcare systems, and corporations in general. We also need to ensure disability cultural competency is incorporated into curricula at the undergraduate and graduate level for medical, dental, nursing and other allied health professional schools." The greater visibility that individuals with disabilities have, the less misconceptions and negative stigma will be associated with disability. Moreover, Gallegos goes on to explain that accurate portrayal of people with disabilities on television and movies will make a considerable difference in how people perceive disabilities and life with a disability.

Not only does Gallegos lead a commendable legal team in creating significant change for the disability community, he also serves as the Chairman of the National Council on Disability (NCD) appointed by President Biden on the afternoon of his inauguration. The NCD's primary responsibilities are advising the President, his administration, Congress and federal agencies on all policy matters affecting the 64 million+ people with disabilities in the country and in our territories. The NCD is comprised of nine council members, presidentially and congressionally appointed, and supported by a team of 11 incredibly talented and committed full-time staff members. The NCD is the smallest federal agency in all of the government, but serves a crucial role for the disability community. Gallegos explains that the role of the NCD will likely expand within the next ten years, and are currently working closely with a number of different legislative offices framing policy recommendations, and providing comments and feedback to various pieces of proposed legislation they are working on that affect people with disabilities.

This advisory role is likely to expand, whereby, with increased resources, at very early legislative stages the NCD reviews and provides input in a more formal and deliberate manner to every federal legislative proposal that addresses or affects persons with disabilities In doing so, this expanded role will allow the NCD to provide greater input and have more influence to legislative and policy-making decisions. As his role as Chairman of the NCD, Gallegos truly is motivated and inspired by the opportunity to have an elevated voice, working on issues that he has focused on as a disability rights attorney–but at the national level– working with the leadership teams of many national disability advocacy organizations, and working with NCD's multi-talented staff and council members.

All in all, change and representation of disability is crucial. Here, in the United States one out of every four people identifies as having a disability. Statistically, in the next couple of years, it's likely that every family in the United States will have a personal connection to disability. The issues that Gallegos and his team are addressing are issues that affect everyone - today's disabled and today's abled.

With this, Gallegos concludes with a reflection: through his work with the disability community, "I learned to fully embrace my disability and once I did, it became easier to advocate for myself and for others."

Disability is

a global public health issue : a human rights issue : a development priority

A FEW FACTS

With Governments help, disabling barriers can be overcome

People with disabilities are disproportionately affected during the Covid-19 pandemic

People with disabilities are vulnerable to poverty

Health care services have not expanded to meet the growing needs of children with disabilities

People with disabilities can live and participate in the community

People with disabilities are more likely to be unemployed than someone without a disability

People with disabilities often do not receive the health care they need

The numbers of people with disabilities are increasing substantially

Source: World Health Organization

MaahsTravels

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Interview with

Ron Pettit

Director, Disability & Inclusion and ADA Compliance
Royal Caribbean Group

by Crystal Vaughan-Gagnon, student at St. Cloud State University

“Plane,” was Ron Pettit’s second word. When he was little, he would go over to his grandmother’s house and watch the airplanes from the nearby airport. He loved that he could hear and watch them take off. His happiness in watching planes when he was so young was just the beginning of his passion for travel. It wasn’t until Ron was about 3 years old that he found out he was hard of hearing.

After Ron's parents made this discovery, they took him to a doctor to find out what they could do to support him. The doctor told them that Ron may need to go to a school for the deaf and that if he went to public school the best he would be able to do was be a “C-Student”. Instead, Ron said that his parents gave him the opportunity to be whomever he wanted to be. Ron went to public school and earned all A’s and B’s.

Ron moved often when he was younger, referring to himself as an “Army Brat”, eventually he settled in Worcester, MA. When he was growing up, Ron wanted to work with an airline saying that he was a bit of an, “airline geek.” His passion for planes and travel had always been a constant in his life. Ron went to Bridgewater State College in Massachusetts because they had an aviation program. For Ron to major in airline management, it was required that he got his private pilot license. Because of hearing loss, Ron felt he was unable to fulfill this requirement, so he changed his major to communications. It wasn’t until he was in his senior year of college that he found out that that pilot license requirement could have been waived. This was when Ron realized that he would need to self-advocate, he said, “I should have spoken up for what I wanted and said, ‘This is what I want to do, how can you help me achieve this?’” It was around this time that Ron said he started to understand that even though he didn’t identify as a person with a disability in the past, he began to realize he was a person with a disability. Ron says that his hearing loss is a part of who he is today, because of what he has had to adapt to and overcome.

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Toward the end of his senior year, Ron applied to work at Northwest Airlines. He started in Worcester, Massachusetts and worked at a small station to load luggage, then he moved up in the company and began checking people in, before he was relocated to Boston and Minneapolist/St. Paul and worked there for 17 years. Half of his time spent there was working the Northwest Airlines Headquarters where he was involved in accessibility for airlines and travel. He created the industry leading Customer Advisory Board on Disability. Ron realized that he had a deep passion for this work and helping others with disabilities because he believed, "Everyone should get a vacation."

This drive and passion made Ron realize he wanted a career that focused on accessibility full-time. Ron saw a job opening for Access Manager on the Royal Caribbean Cruises. He read the job description stating that the Royal Caribbean was seeking someone to be a leader for cruise travel for people with disabilities and looking for someone who was innovative, bold, and would take initiative. This position was perfect for Ron. He applied and was hired 3 months later.

Ron is now the Director of Disability & Inclusion and ADA Compliance for the Royal Caribbean Group, "What excites me in my role is the ability to make travel accessible for everyone everywhere including people with disabilities. I can help make their vacations effortless and easy so they can focus on having a great, and accessible, cruise vacation experience and making those wonderful memories with their families and friends."

As the Director of Disability and Inclusion, Ron consults with other departments and senior leaders, and leads a team of people to provide accessibility on the high seas in a variety of ways. In 2014, Royal Caribbean International became the first Autism-friendly cruise line. Every year since has doubled the number of guests with autism on the cruise lines. They have also hosted full ship charters where deaf and hard of hearing guests were the majority rather than the minority. Sign language interpreters were provided for equal access to onboard entertainment and activities, hearing accessibility kits were included in rooms, where if someone knocked on the door an alert would signal.

Two-story urban Loft suites were made accessible and 90% of the time these suites and accessible staterooms are booked by someone with a disability who need these accessible accommodations. The Flow Rider, a surf simulator on the ship, allows staff to work with people one on one and give additional time to those who need it. The ice-skating rinks, rock climbing walls, and carousels at sea are each additional examples of accessibility that the cruise line provides. Ron finds this career rewarding.

Royal Caribbean Cruise Line
Accessible Stays

"I want to leave a legacy, and this is how I do it." *- Ron*

Ron is constantly asking himself how his team can make the ships and the experiences on the ships more accessible and more inclusive and focuses on how to make the impossible possible. Ron shared, "It's important to be more inclusive because it makes it a better world, a better place for us to live in, and makes us relate to each other on a more human level. When we're more inclusive, we can celebrate the similarities as well as the differences."

Vision tech developments give a glimpse of the future

by *Jennifer Wills*

Advances in assistive technology have removed many access barriers for people with vision loss. But it's the development of visual prosthesis that has the potential to offer a whole new way of 'seeing' the world.

The incredibly complex structure of the human eye – with more than two million interacting parts – makes restoring someone's sight a formidable challenge. But it's not an impossible one, as the bionic eye, or visual prosthesis, to use the medical term, featured for decades in sci-fi fantasy films and TV shows, is now a reality.

'Enabling a patient to see again is our dream. A dream that we believe can come true,' said Serge Picaud, director at Institut de la Vision, a leading research centre on eye diseases in Paris, France.

As a world leader in the development of prostheses concerning the retina (a layer of cells at the back of the eyeball and which are sensitive to light), Picaud is coordinating ENTRAIN VISION, a network of experts from all key disciplines related to visual restoration – from neuroscience and engineering to pathology and machine learning. Together with 15 early-stage researchers, they are working on novel technologies for restoring patients' vision.

'It may sound a little like science fiction,' said Picaud, describing the prostheses at the retinal and cortical level (cerebral cortex or outermost layer of the brain).

'Currently, there are no commercial cortical prostheses, so this research provides a major opportunity to develop them, and we have a team working on this,' he explained.

For millions of patients who are losing their sight or are already blind due to a damaged connection between the retina and visual cortex, a cortical prothesis is the only option.

Seeing is believing

The idea to electrically stimulate the human visual system is not new – it was first described more than 200 years ago. But rapid advances in neural engineering and micro-electronics have paved the way for more advanced cortically-based visual prosthetic devices.

'The idea is to use a type of electronic device to electrically stimulate the remaining nerve cells. So, after having lost part of the "circuit", you replace it with an electronic device,' said Picaud.

One of the ENTRAIN VISION partners recently implanted a microelectrode array composed of 100 microneedles into the visual cortex of a blind woman. With the implant, she was able to identify lines, shapes and simple letters. 'These results are very exciting because they demonstrate both the safety and efficacy of this technology and can help to achieve a long-held dream of many scientists: to transfer information from the outside world directly to the visual cortex of blind individuals, restoring a rudimentary form of sight,' explained Picaud. 'This work is likely to become a milestone for the development of new technologies that could help to transform the treatment of blindness. However, more studies are still needed.'

The use of electrostimulation to recover an individual's sight is just one novel approach being studied, but there are others.

Developed in the 2000s, optogenetics is a biological technique that uses light to controls nerve cells or other cell types.

'There is already one patient in France who can see using this,' highlighted Picaud.

The patient Picaud refers to was diagnosed with the neurodegenerative eye disease retinitis pigmentosa, which affects more than two million people worldwide destroying their retinal photoreceptors. Thanks to groundbreaking research with Gensight Biologics, the patient's sight has been partially restored using light-sensing proteins first found in algae.

The third exciting technology that researchers have set their sights on is virtual reality.

'In Paris we have a setting like a movie theatre (Streetlab) where we can test a patient's vision,' explained Picaud. 'It could be, for example, a room full of obstacles. So, once the patient has a device implanted, we can test it using this platform. However, it's not easy to validate a device in other centres outside of Paris, because the platform cannot be easily recreated elsewhere due to its size. This is where virtual reality steps in.'

For instance, a virtual reality headset can allow users anywhere in the world to experience the same conditions as those in the Paris theatre. 'It can also help us understand what the most important parts of an image are for a patient so that they can recognise their friends or ways to move about a room,' added Picaud.

Such technologies will help people suffering from loss of sight to regain their independence. But what happens if both sight and hearing – our two most important senses – are severely impaired?

Researcher uses virtual reality (Streetlab) to test a patient's vision © Serge Picaud, 2019

Solutions for life without light and sound

For the millions of people who live with deafblindness, the sense of touch is central for perceiving and interacting with the world.

'Being informed and able to communicate are central to everything we do, but you cannot interact with your environment if you are unable to gain information about it or communicate with people and your surroundings. So, we focused on improving communication for people with deafblindness,' noted Nasrine Olson, senior lecturer at the University of Borås and coordinator of the SUITCEYES project.

The result was a smart, tactile interface that extends the perception and spatial orientation of the user, making it possible for them to interact with others. The technology was nominated for an Innovation Radar Prize.

Capturing the environment using computer vision

Describing the ins and outs of the technology, Olson said: 'First, our "haptic intelligent personalised interface" also known as HIPI captures the environment using computer vision and sensor technologies. The camera, sensors and computer vision algorithms collectively detect and recognise objects, scenes and faces. An object can be "a chair" or "a cup", a scene can be "a corridor" or "an office" or "a bathroom". The system also detects faces and whether they are known to the user or not. The sensor technologies also observe the distance between things.' If the user is looking for their cup of coffee, for example, the HIPI will observe that it is on a table three metres away, to the left of the user.

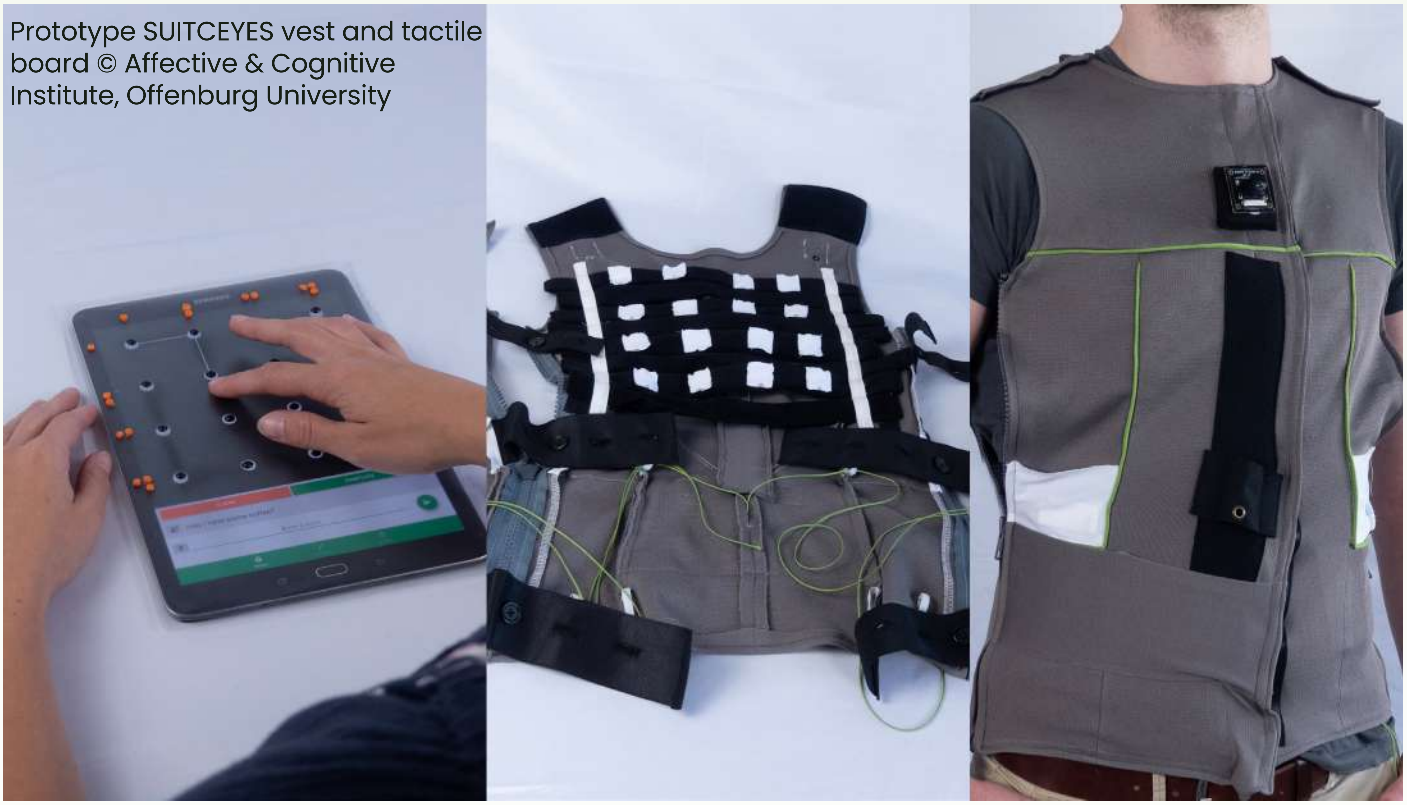
Once the platform has all of this information, what does it do with it? How do we communicate this information to the person who needs it? 'We have created haptograms, for conveying messages to the users. A haptogram is basically a haptic pattern that carries a meaning, for example "happy" to the user. It does this by using vibro-tactile actuators, which are small electronic devices that vibrate. They can be placed on different parts of the body,' explained Olson.

Various prototypes have been developed that integrate the technology into clothing. 'This includes a range of vests, as well as a dress to show how the technology can be worn while looking fashionable,' said Olson. There's also a version called "chairable" that can be mounted onto the back of an office chair to convey messages to the person seated.

The possibility of smart wearables and soft interfaces that enable people with deafblindness to obtain information about the environment will facilitate independent living. The project even added a Covid-19 feature that allows facial recognition with masks.

New features include the ability to send the same haptic information to multiple people at the same time, whether close-by or across long distances. 'This was tested by our colleagues in the Netherlands by sending haptic messages to colleagues in Germany,' said Olson. But what's truly unique about the project is its holistic approach that included extensive user and policy studies, network building, technological innovations and gamification for enriched user experience and learning possibilities.

While it's likely to be some time before the benefits of this technological breakthrough are widely experienced, the future prospects are exciting. In the meantime, researchers continue to envision a future where sight can be restored.



Prototype SUITCEYES vest and tactile board © Affective & Cognitive Institute, Offenburg University

The research in this article was funded by the EU.
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Read the original article.

Omar Harrinanan

"Do not give up on yourself"

Omar Harrinanan has a keen interest in anything tech-related. He spends a significant amount of time seeking out knowledge that relates to his two passions, information technology and gaming. Many hours are spent learning from his favourite YouTube channel, Linus Tech Tips, and one of the things he really hopes to do one day is to build his own computer.

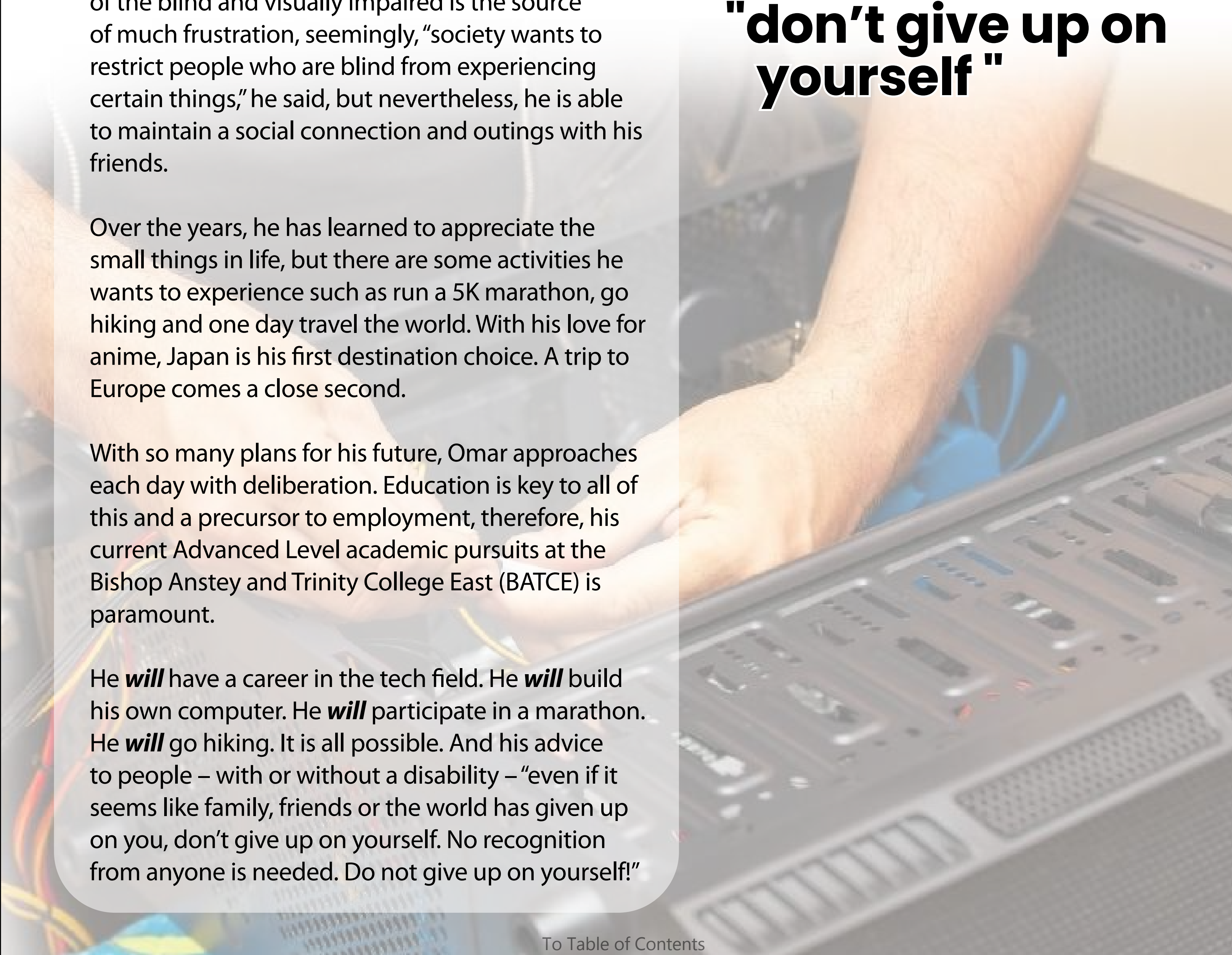
The fact that Omar is visually impaired is no deterrent. Now 20 years old, he has become used to not having full use of his sight. When he was 9, he experienced retinal detachment after a child bumped into him at school, leaving him completely blind in his right eye. In his left eye, there is partial retinal detachment and Strabismus (crossed eye), rendering him with very low vision, but Omar is unfazed.

His determination to succeed at whatever he chooses to do was profoundly reflected in his results at the Caribbean Secondary Education Certificate (CSEC) examination on his island on Trinidad and Tobago. Omar performed exceptionally well, earning A's and B's in English, Spanish, Mathematics, Human and Social Biology, Accounting and Social Studies. He earned distinctions in Information Technology and Principles of Business. Omar is understandably proud of this achievement but modestly admits that the success he enjoys today is not attributable to him only, but to the strong support system of teachers, student aids, friends and family.

Positivity and an infectious sense of humour are his constant companions. Laughter is inevitable when one speaks to Omar and you can't help but notice the depth of his confidence and determination to succeed. He admits that his family is not wealthy and so resources available to him are not many, but he will continue to pursue his education and knows that a career in the technology industry will one day become a reality.

Good humor and an upbeat personality are what you see when interacting with Omar, but he does admit that many disappointments have littered his path over the years. Mental resilience has seen him through them all but he is still working on accepting that there are some things he won't be able to do, like get a driver's license, for instance, which he really wishes was possible.

Independence is important to Omar and the fact that society does not seem to consider the needs of the blind and visually impaired is the source of much frustration, seemingly, "society wants to restrict people who are blind from experiencing certain things," he said, but nevertheless, he is able to maintain a social connection and outings with his friends.



Over the years, he has learned to appreciate the small things in life, but there are some activities he wants to experience such as run a 5K marathon, go hiking and one day travel the world. With his love for anime, Japan is his first destination choice. A trip to Europe comes a close second.

With so many plans for his future, Omar approaches each day with deliberation. Education is key to all of this and a precursor to employment, therefore, his current Advanced Level academic pursuits at the Bishop Anstey and Trinity College East (BATCE) is paramount.

He ***will*** have a career in the tech field. He ***will*** build his own computer. He ***will*** participate in a marathon. He ***will*** go hiking. It is all possible. And his advice to people – with or without a disability – "even if it seems like family, friends or the world has given up on you, don't give up on yourself. No recognition from anyone is needed. Do not give up on yourself!"

Omar believes that despite his sight impairment, a career in the technology industry will one day become a reality.

His advice: "don't give up on yourself "

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Dementia Advocacy

This is an important time for Dementia advocacy. As COVID-19 has become a global health priority, other health diseases such as cancer and dementia have been highlighted in the media. This is a cause for concern. As information needs to be disseminated to families and caretakers, the work has only increased since COVID-19.

Inclusion of older people in all aspects of governance is a key action to ensure that policies are developed and acted on for the greater good of vulnerable communities. Funding for dementia organisations is also imperative to ensure community groups have accessible funding to continue their projects for care homes and older people. Most were isolated during this time, which resulted in lack of human interaction.

There needs to be more support for creative engagement programmes that connect older people with the world around them, to improve their mood and quality of life.

Another area where people with dementia need to be amplified is through the media. We are consuming more social media content like never before. It is important that older people are celebrated and are shown in their truest form. An older man on a wheelchair is not the only indication of an older person, we are living in an aging population but a very lively one. We have a lot of people who are living well with dementia. Stories of hope are important to tell because it provides real hope for families who have someone with dementia.

It continues the conversation of seeking therapy and working towards a dementia diagnosis and hopefully a cure one day.

Let's talk Dementia Awareness . . . in the next issue, we'll examine the inclusion of people with dementia in local government and other areas.

Rianna Patterson is a personal development coach, TEDx speaker founder of a youth-led dementia charity called Dominica Dementia Foundation which she launched when she was 18, in memory of her grandfather. She is also the film director of Dementia: *The Island Journey film, a documentary on dementia in the Caribbean.*

Dominica Dementia
FOUNDATION

CARING FOR SOMEONE WITH DEMENTIA

1. Be gentle, patient, and treat them with dignity and respect.

2. Some may need help with carrying out everyday tasks. Tell them what is being done step by step and allow them to participate as much as possible.

3. Maintaining a routine is important.

4. During conversations, speak in a soothing tone. Keep the conversations going for as long as possible. Do not try to finish their sentences as this may be frustrate them.

5. Do not argue with them

6. Keep objects that they are familiar with in sight

7. If the person with dementia becomes aggressive, leave the area, if possible, but first ensure that there are no objects around they can use to possibly hurt themselves. Try to identify the triggers.

8. Smile and maintain a pleasant demeanour throughout your interaction with a person with dementia. Show affection by your body language and gentle touch.

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The Alinker:
A Vehicle for Change

Written by Shana Jones

(synopsis of a Sophia Bishop ELEVATED Conversation with BE Alink)

BE Alink,
Founder of the Alinker

She says she's not an activist, but I respectfully disagree. She has built schools in Afghanistan and taught carpentry to deaf children in Kenya. She challenges the refuge of comfort we tuck ourselves into by refusing a seat on the othering bandwagon. She personifies a fierce defiance of the mindsets driving the ism's in society, choosing to see a single human race made up of diverse parts instead of different sub-elements struggling to co-exist. Yeah, I'd definitely call her an activist, and her current tool of activism is her revolutionary Alinker "walking bike" designed to re-imagine life for people using mobility devices (MD).

"Over my dead body will I ever use one of those things!"

The Alinker story started with these words uttered by BE Alink's mother while on a trip to the market back in 2011. Noticing a group of elderly people happily chatting away in their scooters and wheelchairs, she inadvertently made a judgement about a group of people she could easily become a part of someday. It was a moment of reckoning for BE, who had always been fueled by a passion for justice and inclusion. She believed strongly in the right to live and express life on one's own terms, free from the constraints of society's expectations. She was keenly aware, however, that some people, especially those needing mobility assistance, continued to be systemically "othered" by society and cut off from enjoying even life's simple pleasures.

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"…for those who want to live despite mobility challenges." BE set about designing a solution, knowing it would have to be something her mother would want to use. Enter the Alinker, a revolutionary non-motorized bike without pedals that enables the user to work leg muscles and be mobile while being seated. The device is built for 3 inseam ranges and is useful across a spectrum of activities: a young child with cerebral palsy stabilizes himself during a virtual exercise program, a lady with multiple sclerosis (MS) makes the short trip to the corner shop, and a Paralympian flies around a track in preparation for a marathon. The limits of the Alinker really are the limits of the user.

"A vehicle for change." Beyond the obvious physical advantages of the Alinker, it addresses other deeper issues. On the surface, its value stems from the movement it allows users, because movement equals independence, which equals value, right? Of course. Less visible, however, is the social divide between those who need mobility devices and those who don't: if you see me in a wheelchair and have to approach me, you probably feel a twinge (or more) of discomfort. In your mind, my immobility promptly groups me in a category of person unlike and therefore inaccessible to you. This mental sorting process is automatic, natural, and convenient. Human nature pushes you to protect your comfort zone, so in order to deal with the awkwardness, you will either subtly ignore me or display patronizing behaviour towards me. The Alinker addresses this by placing the user at eye-level with others (you're perched on a seat as opposed to seated in a chair), which subtly but very powerfully makes the user more "accessible" to non-mobility device users. Additionally, the innovative design of the Alinker so captivates people seeing it for the first time that their curiosity overrides any discomfort about the person's disability. The device then becomes a conversation starter and therefore a "bridge in the gap" between the MD user and non-MD user.

"A body is what we have, not who we are." Alinker users the world over continues to bring this phrase to life in the way they "bridge gaps" and move through daily life. They fully embrace the idea that their immobility doesn't define who they are; rather, it simply has to be worked into active engagement in all areas of life.

Prominent users include *Colonel Carlo Calcagni*, an Italian military officer-turned-Paralympian who recently completed the London marathon on his Alinker in just over 2 hours; *Roxy Murray*, a London-based fashion influencer, podcaster, and activist with MS who colour-codes her Alinker and other walking aids with outfits for her Instagram posts; and *Selma Blair*, an American actress recently diagnosed with MS for whom the Alinker has become “her way out again”.

“Together we move differently!”

Making “her way out again” means Selma and other Alinker users regain access to the outside world and to a special community in which they thrive and inspire. The Alinker community promotes activity, awareness, and support among users as well as non-users through Facebook and Instagram groups, online networking/information sessions, and exercise programs through the Alinker Academy. To address financial hurdles in purchasing a device, the company offers rent-to-own opportunities and crowdfunding programs through the Alinker site.

The Race to Raise features Alinker record-setters running marathons, races and other events to support campaigns for others to get their devices; so far, 191 of the targeted 200 campaigns have been completed! This translates to “191 times more agency, belonging, [and] mobility”.

From the first Alinker deliveries to ecstatic customers, people previously marginalized by society have been re-imagining and re-purposing their lives.

Yet, for all its reach and impact, the Alinker represents only a single part of a greater company vision to provide access to community, mobility, and healthy food (the company recently opened an accessible farm in Kentucky, USA, where it employs Alinker users). When Barbara founded *Alinker Inventions, Ltd*. in 2012, she realized very quickly that it is first and foremost the access to these key resources that promotes a healthy, fulfilling life. Through innovation fuelled by a passion for justice and equality, the Alinker continues to offer access to such a life that is the birthright of all, regardless of mobility or other challenges.

Colonel Carlo Calcagni (who was exposed to heavy metals in the Balkan war) did the London Marathon on his Alinker in 2 hours and 4 minutes. Two other veterans used their Alinker at the 2021 Boston Marathon weekend to *Race to Raise* for a few other people to get their Alinkers. (**Runs** are done by Alinker users to support others to get an Alinker.)

Alinker published a children's book **"Donny and the Three Strange Nomberts"** in collaboration with the author, *Natalie van Scheltinga*.

TOGETHER
WE MOVE DIFFERENTLY

thealinker.ca

Next stop: a transport system accessible for all

by Elena Pappas

People with a disability can look forward to many new advances in technology to make their lives easier while navigating public transport systems, or even crossing the street, thanks to several new initiatives in Europe.

Once known for its matchstick industry, the small Swedish city of Jönköping has another claim to fame. It is one of the most accessible cities in Europe for people with disabilities.

The winner of the 2021 Access City Award, Jönköping was recognised for its inclusive and universal bottom-up approach. Working closely with disability organisations, city officials rolled out a wide range of initiatives to make buildings, products and environments accessible to as many people as possible.

City-wide improvements include tactile maps and signage, audio descriptions, tactile paving, easy to read facilities, accessible pavements and barrier-free wheelchair access. From the concert hall to the matchstick museum (one of only three in the world), Jönköping's attractions, shops, public buildings and infrastructure meet the long list of accessibility criteria.

Indeed, Jönköping is one of many examples of European cities that are friendly to people with disabilities. And with one in five Europeans living with some form of disability, city actions are proving indispensable in order to cater to a growing need for accessibility.

Making it easier to move around

To rise to the challenge of universal accessibility, cities can benefit from innovative technologies that promote a barrier-free and inclusive society. Solutions may involve the use of augmented reality, wearables and artificial intelligence. These are just some of the smart tech solutions that scientists are co-designing together with disabled persons in line with the EU's Urban Mobility Framework.

Transportation researchers in the Netherlands recently made an important discovery by surveying disabled commuters. They learned that the single most popular item in demand amongst users with different types of disability would be a simple, smart information tool. Imagine a special version of Alexa for travel - an interactive accessible journey planner that would greatly improve people's mobility and willingness to travel.

The researchers, who are working closely with a Europe-wide network of disabled citizens and are supported by the TRIPS project, are drawing on this finding to develop and test mobility solution models.

According to Kristina Andersen, Assistant Professor at the Future Everyday cluster of the Department of Industrial Design at Eindhoven University of Technology, a smart planner is needed to provide accurate information on the accessibility of transport. It could include, for example, the availability of seats on the next bus or whether certain accessibility infrastructure is "out of order". The smart planner would provide this information in multiple ways - sign language, audio, lip-reading – as well as be integrated with smart glasses. It would also be free to use and not require registration.

'Poor access to public transport means people are stopped from accessing job opportunities, education, social and leisure activities and other services,' explained Andersen.

"By focusing on the experience and needs of disabled people, we address a wide variety of barriers such as age, health, or language in current urban transport systems.

Professor Kristina Andersen at Eindhoven University of Technology and TRIPS lead.

To showcase how such co-designed mobility solutions can provide inclusive urban transport for all, TRIPS is rolling out case studies in seven pilot cities: Brussels, Bologna, Cagliari, Lisbon, Sofia, Stockholm and Zagreb.

By inviting those with disabilities to highlight the problems they face in using public transport and empowering them to co-design solutions through brainstorming with experts, Andersen and her team hope to address the most serious risk facing people with disabilities: that of social exclusion.

'By focusing on the experience and needs of disabled people, we can address a wide variety of barriers such as age, health or language in current urban transport systems,' said Andersen.

All of this information is not just helping with new innovative services, but also sheds light on what's needed when designing future transport systems.

Leveraging digital technologies

The user perspective is important when designing and testing mobility solutions for persons with disabilities.

In this context, researchers from the MOBI Mobility, Logistics and Automotive Technology Research Centre at the Vrije Universiteit Brussel (VUB) are conducting a pilot study in Antwerp. They are testing a new method to assist visually impaired people at pedestrian crossings by sending audio and vibrating messages to their smartphones, so they can safely cross the road.

'In most cities, only a select few traffic lights have pedestrian signs with audible signals,' said Assistant Professor Imre Keseru, who is the lead researcher on the INDIMO project. 'Often, these get installed on demand and cause complaints from local residents due to the noise produced. They are not always reliable and can malfunction. Therefore, more often than not, blind people have to trust in their own hearing to make sure the pedestrian light is definitely switched to green.'

Keseru also noted that until recently, digital mobility solutions were mainly developed to address the needs of average users, leading to the exclusion of specific groups with very specific needs.

Additionally, 'while significant achievements have been made mainly in terms of improving the physical accessibility of transport, digital accessibility and inclusion have not been fully addressed,' said Keseru.

INDIMO researchers are tackling this issue, working with policymakers, tech developers, transportation operators and persons with disabilities. They have created a toolbox featuring universal design principles that include accessibility standards for transport services, plus cybersecurity and privacy guidelines to encourage more accessible and inclusive digital mobility solutions for all.

While significant achievements have been made, mainly in terms of improving the physical accessibility of transport, digital accessibility and inclusion have not been fully addressed.

Imre Keseru, Urban Mobility Assistant Professor at Vrije Universiteit Brussel and INDIMO lead.

While the first version of this toolbox is being tested in Antwerp with the intelligent traffic light system, four additional pilot projects (in Spain, Italy, Germany and Israel) are exploring innovative solutions such as on-demand ride sharing in tandem with multimodal route planning.

What all research projects have in common is a call for better digital services to aid disabled users' mobility and overall quality of life. They also highlight the need for better digital education and tools to enhance social inclusion for those at risk.

Online holiday booking site for travellers with a disability

Planning a holiday or business-related travel is usually more challenging for those with disabilities, who may worry about whether their accommodation will have access ramps for wheelchairs or information in braille, for example.

A unique online booking system for accessible accommodation may help solve this problem. Developed by a Swedish father whose son suffers from a muscle disease and needs a wheelchair when travelling, Handiscover aims to simplify the search for special accommodation. Simply put, it's a community-based holiday accommodation-booking website with a unique classification system that allows users to search based on their level of mobility.

'We take into account issues like the number of stairs, distance to the parking space, the width of doors,' said Sebastien Archambeaud. 'This information makes it easier to choose where to stay.'

Building on Handiscover, he has also launched a secondary website to assist hotels, retail shops and other businesses to better understand accessibility and disability through education workshops.

70% of disabilities aren't visible. We tend to associate disability with a wheelchair, but don't forget the visually and hearing impaired.

Sebastien Archambeaud, Founder & CEO, and Handiscover leader.

'With half of the 65+ age group having some form of disability, and 70% of all disabilities not visible, it's important not to associate disability with a wheelchair,' noted Archambeaud. 'Let's not forget the visually and hearing impaired.'

By placing technology at the heart of building and revamping our cities and transportation systems, digital technology and innovation now have the potential to make life easier for people with disabilities.

If you liked this article, please consider sharing it on social media.

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This article was originally published in Horizon, the EU Research and Innovation magazine.
Read the original article.

> **‘With half of the 65+ age group having some form of disability, and 70% of all disabilities not visible, it’s important not to associate disability with a wheelchair,’**
>
> ~ Professor Kristina Andersen

Canadian Association of the Deaf

Association des Sourds du Canada

We are Busy!

by Jim Roots,
Executive Director

The Canadian Association of the Deaf – Association des Sourds du Canada (CAD-ASC) protects and promotes the needs, rights, and concerns of Deaf people in Canada. We are the national information, research, and community action organization of people who are culturally and linguistically Deaf. We partner with national organizations of persons with other disabilities including Deaf-blind, blind, developmentally delayed, intellectually disabled, language deprived, and literacy challenged. We combine the purposes of a research and information centre, advisory council, representative body, self-help society, and community action group. Founded in 1940, we are the oldest national-level disabled consumers organization in Canada.

Our Board of Directors meets at least monthly. Following election at the Annual General Meeting last summer, the directors are now choosing their involvement in CAD-ASC committees. We have 17 committees, e.g. education, Deaf-Blind, women, Indigenous, francophone, youth, seniors, strategic planning, mental health, communication etc. We have two vacancies on the Board, so we are currently looking for a new vice-president and a new communications director. In addition, our staff is transitioning, with a new Executive Director expected to be hired in January 2022

Our Strategic Plan is continually being updated as we reach out to include diversity and cross-sectoral members and issues. The long-awaited new design for our website (www.cad.ca) is finished, but now we have a long task ahead of us to update the website content. Our goal is to finish March 31st. We are active on social media with daily postings. We also have a monthly newsletter for our members, in four languages: ASL, LSQ, English and French.

In 2021 we provided more than 50 webinars; more than 300 people participated, and 2,000 more people viewed them later.

We currently have two active projects.

Project #1 involves consulting our communities to gather

ideas, recommendations, and feedback on suggestions for federal accessibility standards. Project #2 examines viewer preferences regarding the captioning of live hockey and basketball telecasts. That project was on hold for a year because of COVID but it is back in action now.

In the spring we will start *Project #3*; the topic is accessibility of banks and financial institutions for people who are Deaf, Deaf-Blind, and hard of hearing. We hope to get approval for *Project #4*, which involves finding jobs for Deaf youth; and *Project #5,* which will create working partnerships with our affiliated provincial associations to further the inclusion of diversity, both nationally and provincially.

We are advocating for a *Canadian Disability Benefit,* in collaboration with a broad list of organizations and individuals. We work with the *National Network on Mental Health* to get attention on Deaf and disabled mental health challenges. We work with *IRIS Institute* and other organizations to develop a one-stop accessibility website. We're on the council of leaders for the *Pan-Canadian Disability Coalition*.

We're involved in three or four councils on accessible transportation, including those of the *Canada Transportation Agency*, *VIA Rail*, and *Spinal Injury Canada*. We're partners with *Ryerson University* in their project about captioning. We're partnering with the *Canadian Nursing Students Association* to offer financial support to Deaf and Deaf-Blind nursing students.

We have a representative to the *Canadian Institutes of Health Research*, and we have a partnership with the *Native Women's Association of Canada* on the topic of Indigenous women and gender-diverse people with disabilities across the country. *Independent Living Canada* chose CAD-ASC to lead a national focus on accessibility for the built environment.

We're members of many government accessibility advisory councils, including a council working to open up federal government service contracts so Deaf people and people with disabilities can sell their services to the federal government.

We partner with *Wabanaki Disability Council* in their project about how Indigenous people approach disability. We're the only non-Indigenous organization invited to work with Wabanaki. It is a great honour!

We're involved as leaders of the national disability coalition working on *MAiD (Medical Assistance in Dying).* This coalition hired ARCH Disability Law to bring our concerns to the international level. The *Organization of American States* has invited the coalition to present our concerns in a private meeting in late December. CAD-ASC does not oppose medical assistance in dying; CAD-ASC's priority is communication in making decisions about MAiD. We believe the provisions in Canada's MAiD legislation are not strong enough in ensuring Deaf, Deaf-Blind and hard of hearing people will receive assisted-death information in a language and cultural format that matches their communication abilities and skills.

Our past president, Frank Folino, is a member of the Board of Directors of the *World Federation of the Deaf*; he participated in a WFD Board of Directors meeting in November. Our new president, *Wissam Constantin*, will participate in a WFD conference in April. We actively supported the International Week of Deaf People in September, and the International Week of Persons with Disabilities in December. Frank continues his involvement in the CRPD review of Canada's report. We're involved in several CRTC proceedings, for example wireless pricing and VRS review. We're negotiating with *Statistics Canada* to improve Deaf and Deaf-Blind access to census and data collection. We contacted Immigration Canada to share our concerns about discrimination against Deaf immigration applicants.

The federal government plans to amend the Official Languages Act, and the Quebec government has presented their new languages legislation. CAD-ASC has concerns about both, and we are working on it.

We are busy!

Israeli tissue engineers 3D-print an ear

Unique scaffold could also be tailored to nasal reconstruction and orthopedic implants.

By *Brian Blum*

A small percentage (0.1% to 0.3%) of babies are born with congenitally deformed ears. This can have a severe psychological impact, and sometimes involves hearing loss.

While surgeons can reconstruct a proper ear using cartilage harvested from the patient's chest, the procedure is not usually performed until at least 10 years of age.

Researchers at the Technion-Israel Institute of Technology and Sheba Medical Center have developed a way to 3D-print "scaffolding" as the basis for a replacement ear.

The scaffold, which allows for the formation of an aesthetic and stable auricle (the visible part of the external ear), is designed from a CT scan of the patient's ear and can be performed on children as young as six years old.

The biodegradable scaffold forms chondrocytes, the cells responsible for cartilage formation, and mesenchymal stem cells. Pores of varying sizes allow for cell attachment to form stable cartilage. The procedure has so far been tested on lab rats. The researchers monitored cartilage formation within the auricle construct in the lab for between 10 days and six weeks before implanting it in the test subjects.

The grafted prosthetic ear demonstrated good biomechanical function, the researchers reported in the journal *Biofabrication*.

The project was led by Prof. Shulamit Levenberg of the Faculty of Biomedical Engineering at the Technion and Dr. Shay Izhak Duvdevani, a senior physician in the Otorhinolaryngology Head and Neck Surgery Department and head of the Tissue Engineering Lab at Sheba Medical Center. The protocols were developed in Levenberg's lab under Dr. Shira Landau.

"One of the challenges in the study was to find a suitable 3D-printing method, since fabricating an ear necessitates the use of biodegradable materials that break down in the body without harming it but have an extremely accurate external structure and small pores," said Levenberg.

"We estimate that it will be possible to tailor our technology to other applications, such as nasal reconstruction and fabrication of various orthopedic implants."

This article was originally published on israel21c.org Read the original article.

Dwarfism Awareness

with Danielle Webb

My journey of self-acceptance

. . . in progress

From a young age, I have clear memories of being shamed for my body image and size. From the innocence of my reception classmates saying I "looked funny" . . . to the 15-year-olds shouting "freak" down the secondary school corridors. Be it right or not, I guess you can say "I'm used to it", so more times than not I brush it off... cold shoulder, because truthfully there are not enough hours in the day to give attention to every person who stares at you as you walk down the street, I've mastered the brave face. But that doesn't mean I always want to use it and sometimes the armour you wear on the outside, cannot always protect you from the hurt it causes within.

Before the age of 13 - no one mentioned my size. As far as I was concerned it was no more than a physical characteristic - and even then, I wished every day that it wasn't. I tried to dismiss that it was even part of who I was at all. I was stuck in a trance of longing to be someone else, when truthfully all I really wanted, was to be ok with being me as I was.
I spent a long time waiting for the day *'it was ok'*.

But something I've had to learn as I've got older. Is there is no real point where it suddenly all becomes ok. And accepting this is a hard pill to swallow.

From a secondary school teen, my mental health has been my demon-fed and fuelled by a struggle to find acceptance of the path I was put on. Bullying was also a feeder of that demon - The opinions pressed on me by the wider world- often reformed themselves into my own self-doubts.

Age 15, whilst walking home one evening, I had abuse hurled at me, with cans and footballs thrown in my direction. I've had my face photoshopped on memes. I've been followed and filmed in the streets. Had my social media leaked onto "just for fun pages". I've been called every name under the sun . . . Fat. Ugly. Freak. Monster. Been told that I should've been given up as a child. Some even going as far as telling me my existence on this planet isn't worthy. And for what? Because I happen to be 1 metre shorter than the average adult, my life doesn't hold as much value as if I happened to be 100cm taller?

I'm not going to bore you with the jargon and statistics behind my physique, but the simplest way to explain how my condition became a thing, can be done in two words.

Genetic fluke.

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Neither of my parents have the condition, nor have traces of the gene in their families. Therefore, it was a fluke. A chance. A coincidence. An accident if you will...... whatever you wish to describe it as, no one held any responsibility for it. No one has any control over it. I certainly didn't choose it.
Yet I've had to learn to be ok with its consequences.

So, you know what - I'm entitled to feel a bit pants someday.

But then other days. Most days...It is ok.

Like today. Writing this. I'm ok.

But that doesn't mean today is any more of an achievement to last week when I screamed for my doctor to make it stop.

The truth is we don't always have to be ok with the things that cause us hurt. We don't have to be ok with feeling pained. We don't have to put on a brave face every day and always be used to it - Someday its more than ok to hold our hands up and say you know what- this sucks! But something else I've learned over time, is in the moments of denial . . . the times where we least accept what is in front of us . . . all we really do is add to the fire that we are trying to put out.

What I mean is.
On the days, I hear the shouts on the street. Or the days social media tells me I'm unworthy; where am I getting if I allow myself to repeat those same words and feelings to myself?
Well, I can tell you from experience- it's nowhere nice.

We spend every waking minute with ourselves - and in time I've began to realise that for that reason- my own outlook on myself is probably more important than the satisfaction of an online troll, who probably couldn't even tell you my name.

It would be easy to be bitter. As bitter as the world that surrounds us... And believe me, those feelings don't go unseen. I've cried for days. Prayed for days. I've begged doctors to "take it away", but all the time knowing nothing is going too. This is my card. And it's mine to accept.

But you know what else I've learned?

> "Accepting your disability isn't just a switch you can flick. There are days where you feel so confident and nothing can stop you, and days when someone who probably isn't even looking at you can send you on a downward spiral."

Antibullying photoshoot: 2017
Photo Credit: Miss A. Wait

I named this column

My journey of self-acceptance

. . . in progress

Why?

Because I'm still on it. I'm still learning everyday - and I'm equally making mistakes and digging myself out of those downward spirals everyday too, but in making those, mistakes I'm finding in myself the strength to accept the things that part of me might still not be ok with.

Somedays I write columns.

Some days I present seminars.

Other days I don't want to look in the mirror
but each of those days are part of the journey.

I don't think I'll ever be ok with being called names on the street - but to be ok with the body I am in, so that I learn to not believe them.

That's where I want my journey to lead me.
That's the path I am on.

A journey of self-acceptance . . . that continues to be a work in progress.

Please Note:

Dwarfism is not an intellectual disability

Parents of average height can have a child with dwarfism

Parents with dwarfism can have an average-height child

People with dwarfism can lead healthy, active lives

Dwarfism is not a disease

The most common type of dwarfism is called achondroplasia. Adult males with achondroplasia has an average height of 131 centimeters (4 feet, 4 inches). The average height for adult females is 124 centimeters (4 feet, 1 inch).

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CNIB FRONTIER ACCESSIBILITY + Craft&Crew join forces to break barriers to accessibility.

Read how these organizations are continuing the push for “Accessibility Now”

“Digital accessibility is critical to Canadians with disabilities in many aspects of life, including education, employment, government, commerce, health care, recreation and more,” says *David Demers, Executive Lead, CNIB Frontier Accessibility.* He says that people with disabilities have faced unique challenges and vulnerabilities due to the global pandemic. From equitable access to healthcare, information, and communications, digital accessibility has never been more important than it is right now.

Advancements in technology have brought about innovations in accessibility, making it easier for people with disabilities to access digital information. However, as technology continues to evolve, it has become increasingly difficult to ensure that all digital assets can be accessed by everyone.

This creates a significant barrier as **there are roughly 2.2 billion people worldwide who have vision impairment.** Canadians with disabilities have an annual purchasing power of $55 billion. But accessing this significant market segment can only be achieved through universal design.

When it comes to design, accessibility is often treated as an afterthought. An overwhelming number of websites fall short of basic accessibility requirements. With compliance deadlines looming in Canada and abroad—there is no time to waste.

“Beyond accessibility-based laws and government requirements, there’s a good reason to make your website and digital assets accessible: It’s just good design,” says *Dave Hale, Partner at Ottawa, Ontario based website production company Craft&Crew.* “When you make an accessible website, you’re making a website that will be enjoyed by everyone, and will perform well, too.”

“The web is for everyone. Universally accessible websites make it possible for everyone, regardless of their ability to

participate socially and economically," adds Demers.

Together, CNIB Frontier Accessibility and Craft&Crew have partnered to provide businesses with expert information about the accessibility of their digital properties, with an added lens on design and user experience.

Who benefits?

People with disabilities use technology – like telephones, smart TVs, websites, mobile apps, software, and interactive service screens – every day. They have the right to do so freely without barriers and have equal access to information, products and customer services online. Many people have invisible disabilities or may not self-identify as having a disability. Populations are aging and people will continue to need simple, clear and effective interactions and communication. Cognitive disabilities and diverse neuro-abilities such as dyslexia, autism, ADHD and dyspraxia are being recognized in youth earlier.

Being accessible helps everyone

An accessible website must go beyond ensuring proper colour contrast for users surfing the web. While Web Content Accessibility Guidelines (WCAG), are promoted across Canada, the province of Ontario has the Accessibility for Ontarians with Disabilities Act (AODA). It's an act that aims to ensure that Ontarians living with disabilities have equitable access to goods and services, digital materials, accommodations, employment, buildings, premises, and more.

The act aims to level the playing field for people with disabilities and is based on the international standards set by WCAG. AODA plays an especially important role in the push for accessibility, as it is part of a larger provincial goal of making Ontario accessible by 2025. Craft&Crew also recently partnered with Siteimprove, a software provider who offers accessibility checks and tools, to hold a webinar on AODA guidelines for B2B businesses. See the recording here.

When universal design is prioritized, everybody wins.

David Demers
Executive Lead,
CNIB Frontier Accessibiity

About CNIB Frontier Accessibility

CNIB Frontier accessibility is a leading Canadian organization that specializes in accessibility consulting services and provides product expertise in accessible technologies. CNIB Frontier Accessibility's mission is to help private and public sector organizations design innovative and accessible solutions for their business needs.

As a social enterprise, 100 percent of the revenue raised by CNIB Frontier Accessibility helps fund CNIB's charitable mission to provide innovative programs and powerful advocacy that enable Canadians impacted by blindness to live the lives they choose and tear down barriers to inclusion.

For more information about our solutions,
visit https://frontier-cnib.ca/

About Craft&Crew

Craftt&Crew is a full-service website production company that works to help brands understand and increase the value of their websites while fixing a broken agency model. Our company is profitable without relying on overtime, employs people who are paid fairly and equitably, maintains an average client satisfaction score of 93%, and puts people (not politics) at the centre of our strategies.

For more information,
visit https://craftandcrew.ca/

Dave Hale
Partner, Craft&Crew

How these two organizations are working together to tackle barriers to website accessibility

Craft&Crew is an Ottawa-based website production company that has partnered with CNIB Frontier Accessibility to examine the digital compliance and accessibility of organizations within Ontario.

The partnership came about when Craft&Crew received an influx of requests from businesses that were unsure how to make their digital assets accessible and comply with legislation. This sparked an exploratory conversation with CNIB—which transformed into a business partnership to address website accessibility. All proceeds from website accessibility audits conducted by the two organizations are directly reinvested into CNIB's charitable programs for Canadians living with sight loss.

Ensuring equitable access to digital materials

Ensuring equitable access to digital materials

CNIB FRONTIER ACCESSIBILITY

- AND -

Craft&Crew

WEBSITE ACCESSIBILITY MATTERS FOR ALL.

There are 6.2 million Canadians (nearly 22 percent of the population) living with vision loss and other disabilities. Accessible websites matter to these millions of Canadians, and the positive user experience of an accessible website matters to millions more.

Contact Craft&Crew

about making your website accessible for all of your visitors.

Spotlight on Entrepreneurs with Disabilities

1 Autistic self-taught artist and designer

Margaux Wosk (they/them)

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Margaux Wosk (they/them) is an autistic self-taught artist and designer as well as an activist and advocate for people with disabilities. They fight really hard for those who own their own business so that these entrepreneurs are able to have the same rights and benefits that are available through organizations that hire people with disabilities.

They also engage in public speaking and through everything they do, passionately strive to break down barriers that exist as it relates to what is generally believed autistic and people with disabilities are capable of doing. Margaux owns an online store on Etsy.

"My online store is reflective of who I am and I use bright colours and creative, cute imagery. I offer autistic and neurodiversity pride items as well as a wide variety of things: patches, stickers and so much more."

Their artist pseudo name is **Retrophiliac** which means lover of past things. *"I am very inspired by the 60s, 70s, 80s and 90s and it is reflected in all of my work and even my personal style. I came to make a change for many people are not just myself. I find strength in my work and the overlap of my activism, advocacy and art."* ~ Margaux Wosk

Support entrepreneurs with disabilities

www.retrophiliac.etsy.com

Margaux is active online:

Made by Autistics Community

Made by Autistics Marketplace

Blog: www.navigatingjourney.com

Website: retrophiliac.etsy.com

@Retrophiliac

@Retrophiliac

2

COLLETTEY'S COOKIES

Collette Divitto is a bright, caring, 30 year-old woman with a true sense of who she is and where she wants to go in life. She also has Down Syndrome, but this hasn't stopped her from her many achievements.

Read about her here and order some of her delicious cookies from her website **www.Colletteys.com**

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Spinal Cord Injury

by Spinal Cord Injury BC

The spinal cord is a thick bundle of nerves that connects the brain to the rest of the body. It acts as an information highway, sending messages back and forth. A spinal cord injury, or SCI, refers to damage to the spinal cord. This can lead to a loss of muscle movement, called paralysis, and a loss of sensation. It can also affect basic body functions like urination, blood pressure, and breathing.

The effect of a spinal cord injury depends on the level of the spinal cord that is damaged, as well as the degree of damage. The injury can happen in your neck, back, or lower back. The higher the injury, the more parts of the body are likely to be affected. If the injury is at the level of your back or lower back, the muscles in your legs and possibly your trunk may be affected. When you experience paralysis in your lower body, this is called paraplegia. A higher injury, at the level of the neck, can affect the hands, arms & breathing muscles in addition to the trunk and legs. This is called quadriplegia or tetraplegia.

In Canada, there are approximately 86,000 people living with an SCI. It is estimated that there are 12,000 people in BC living with an SCI and this number continues to grow annually.

Spinal Cord Injury BC (SCI BC) is a non-profit organization dedicated to helping people with spinal cord injuries and related disabilities, adjust, adapt, and thrive.
Our vision is that all British Columbians with spinal cord injuries and their families have the support and knowledge they need to live well and be active participants in their communities.

Since 1957, we have been working towards this vision through two core programs: our Peer Support Services and Information Services.

Our Peer Support Services, also known as our Peer Program, provides social connections, mentoring, community events, and unique life experiences to individuals with a spinal cord injury or a related disability, and their families and friends.

Our Information Services help people access all kinds of info relevant to living well with a spinal cord injury.

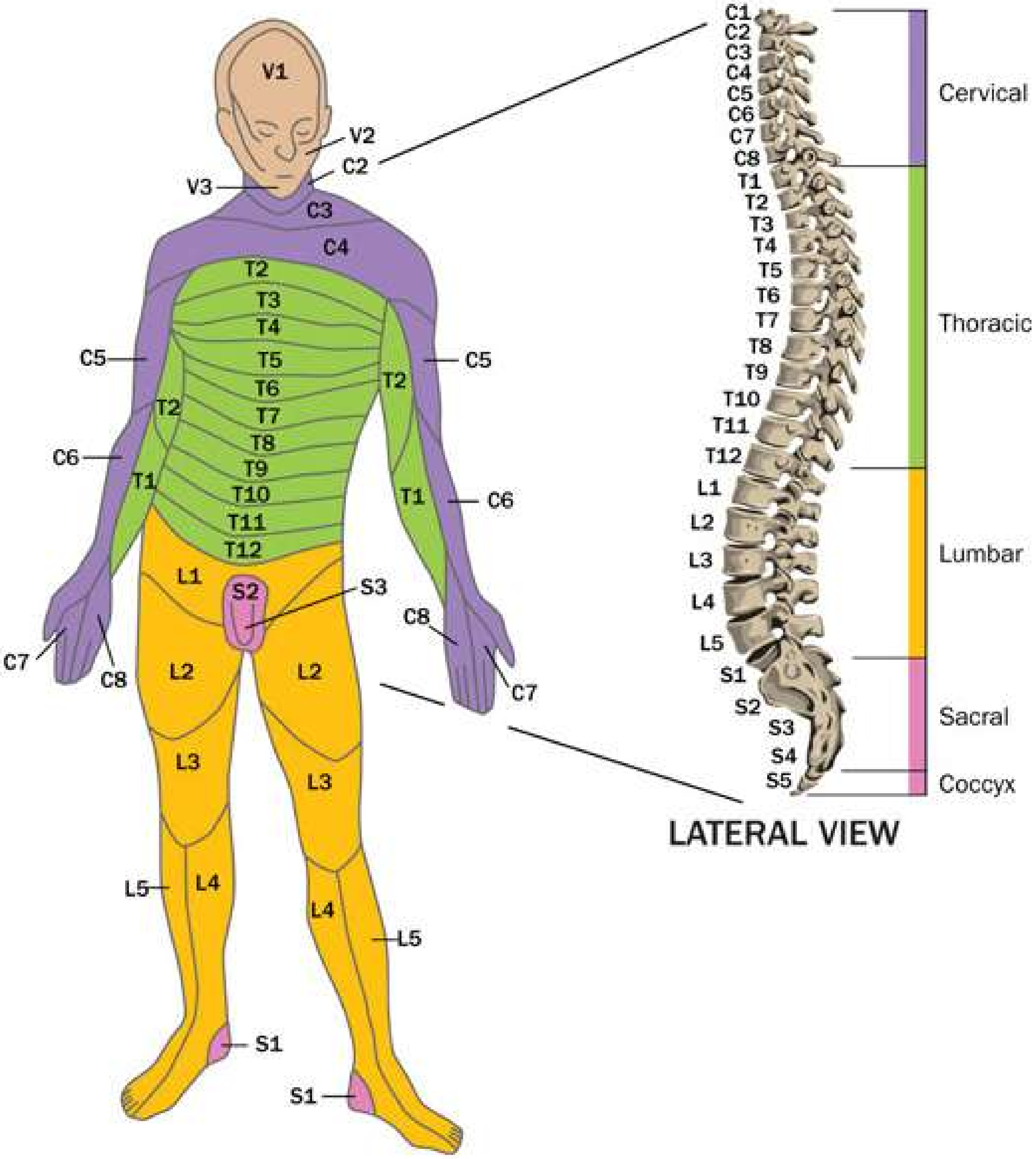
We provide a free online SCI Info Database of over 800 resources and operate a toll-free InfoLine to answer questions and provide support Monday-Friday.

Learn more about SCI BC
www.sci-bc.ca

The Peer Program

Information Services

You are encouraged to visit the **Living with SCI** website
to learn more about spinal cord injury, how your body works after an injury, and
access helpful tools and resources.



The illustrated diagram provides a colour coded overview of the general areas affected by the location of the SCI

Spinal Cord Injury BC


Elena and Brooke

An ELEVATED Conversation

with Elena & Brooke, Founders of Wives and Girlfriends of Spinal Cord Injury (WAGS of SCI)

Brooke Pagé and **Elena Pauly** of Vancouver, BC, started the Wives and Girlfriends of Spinal Cord Injury (WAGS of SCI) group after becoming caregivers for their partners, both of whom are quadriplegic. In 2014, Evan, Brooke's boyfriend at the time, got injured at work when a load of unsecured flooring fell on his head, breaking his neck. After the injury, the couple married in 2016 and Brooke is now his full-time caregiver. Elena's boyfriend, Dan, became severely injured in 2016 after jumping into a shallow pool while both were on vacation in Cuba.

WAGS of SCI began as a meetup and support group exclusively for wives and girlfriends of men who have sustained a spinal cord injury. Although their lives of both women have changed dramatically since their partner's life-altering injuries, they remain resolutely by their side, showering them with love and support, while through their support group, encouraging other women caring for their partners with spinal cord injuries to do the same.

During the insightful hour-long video Conversation, their frustration with the government funding process connected to home health care and the need for more free mental health support were passionately discussed. It quickly became evident that their support group provides significant help to many other women in similar situations

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and through their on-going interaction, they are able to share coping mechanisms. One of the more frequently asked questions is whether sex with their partner is still possible and the answer is "yes." It may take a different form for different people, but it can be done, they shared. Sometimes it looks a little different from traditional sex… "but there are so many options."

Even with government support, the women say caregiver services are far from satisfactory and Brooke had endured "terrible experiences." Some caregivers would show up late and one missed 82 shifts! Brooke shared. "….she said she was coming to the house but I was doing all the work and she was getting paid for those 82 shifts." Elena adds, "Not everyone who is in the field should be in the field." And the reasons for the poor service? Brooke feels that it is because "caregivers are overworked and underpaid" and have too many clients to handle to provide proper care. Elena echoes a similar sentiment stating that caregivers often didn't show up so she had to fill in for them.

Both Elena and Brooke said they had to learn how to "share their space" with daily caregivers, but Elena admits that the "hour and a half in the morning" when they are in the house assisting her partner, this allows her the chance to do dishes, take the dog out for a walk, and get other things done. Elena says it has "taken them a while to find the right caregivers."

At one point during the Conversation, Sophia asks the two women about their feelings as it relates to the role they now play as opposed to the one they played before their partners injury. "We love our partners" was the immediate reply. Elena says in the beginning she was beset with thoughts of "Why me?", but has now adjusted to the new normal. "I kind of forget that Dan's in a wheelchair" she says. Brooke adds that although some wives and girlfriends may find it difficult to accept the new reality of their partners with spinal cord injuries, she never considered any other option but to be with her partner and care for him. "I love this person," she says, "I believe this was put in our lives for a reason."

Watch the entire *Conversation*

The confident
Marcela Marañon
@thejourneyofabravewoman
"I am beautiful the way I am"

At 20 years old, a car accident resulted in Marcela Marañon being confined to a wheelchair, paralyzed from the waist down. Fast forward to today. The adult Marcela enjoys a very influential spot in the social media space. Her Instagram account, @thejourneyofabravewoman, which she started in 2017 "reflects my life," Marcela said. "I feel really brave putting myself out there and doing things" but with 399,000 engaged followers, it is evident that her contribution is felt.

With a degree in communications which included taking social media classes, it was easy for Marcela to identify this medium as one worth using to spread her message. As she navigates her way through the social media biosphere, engaging with her audience and building a strong online community, followers respond positively to her posts, but Marcela admits that her presence on social media goes beyond just her travel adventures posts, fashion and clothing tips. She sees herself as a role model for women with a disability and also those without a disability. With her positive demeanour, she is empowering women to "go ahead and reach for the stars and to do whatever they want to do with their lives, regardless of their physical limitations."

Through social media, Marcela touches the lives of many. She feels blessed by the positive feedback she receives and to realize that many are being helped by the content she posts. Comments from parents and little girls who reach out to her saying, "I have a disability and did not feel beautiful, but because of you, now I do," gives her reason to continue along that Instagram journey. Each of her posts are accompanied by happy feelings as she knows at least one person will be helped as a result. Messages from people seeking advice on the clothing they should buy that will fit them well as a wheelchair user; questions about self-confidence, fashion and accessible travel - these make the time-consuming task of preparing Instagram content worthwhile. Marcela modestly says that she does not like to be called an influencer, but admits that some of her followers are indeed guided by the content she shares, some are inspired by it and based on the feedback she receives, can attribute some of the decisions taken by followers as having being influenced by her.

Marcela's adventurous personality does not permit her to limit herself, so she frequently steps outside of her comfort zone and embarks on many journeys around the world. Travelling solo, she confidently visits countries with which she

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is unfamiliar, sometimes not even being able to speak the same language and oftentimes not being sure beforehand how accessible it will be. But as she checks a completed excursion off her list, it is done with a sense of satisfaction that another accomplishment has been achieved.

Although she has travelled to over 15 countries and experienced some amazing things, her most memorable is climbing Mount Kilimanjaro.

“It was challenging mentally, physically and emotionally but it was a phenomenal experience because I never thought that as a person in a wheelchair, I would have been able to do this and I am very grateful for having had the opportunity to

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do it." The team at Paratrek and their ingenious Trekker was her climbing aid and the euphoric feeling of getting to the top remains with her even today.

Exuding confidence as Marcela does is often not an easy feat. "Everyone has insecurities and so do I, but I do not allow it to show," she shared. "People see confidence in your eyes," she continued, "so I make sure that I maintain that confident feeling as much as I can." She does admit that sometimes it is hard, and not being able to wear an item of clothing or a pair of shoes the way she would like to is bothersome, but that feeling is often just a fleeting one, quickly replaced by positive thoughts.

"I do not like to have people pitying me because of my disability." Marcela continued, "I do not like to be treated as a person with a disability.

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Treat me like you would treat everyone else – like a person!" She worked in the health care industry for 10 years. Her employers knew her needs and met them. She was treated like a regular employee which she appreciated, and at no time was she made to feel any different from the able-bodied members of staff. This can happen in every workplace for other people with disabilities and she urges employers to seriously consider inclusive employment because people with disabilities are people first.

As the charismatic Marcela continues to give followers a peek into her world, companies are recognizing her impact and are capitalizing on her expansive reach to help spread their message. She is a global ambassador for several brands whose products are aimed at helping wheelchair users live full lives. One of these products is the Exoskeleton which she, as an ambassador, has been using as home therapy twice a week since 2014. She has the first unit created and wears it to stand and walk. Marcela enjoys the flexibility of having another mobility option, and her Instagram followers get an insight into a technology which they too can experience as a result of her making them aware of its positive impact on her life.

If you are a person with a disability and specifically a wheelchair user, Marcela says to you:

"Do not be afraid.
It is important to live like if
you do not have a disability.
Do not limit yourself.”

MISS
WHEELCHAIR WORLD

Miss Wheelchair World is an initiative of international stature and a non-profit organization created by The Only One Foundation based in Warsaw, Poland. As an organization highly qualified in ethics and values, Miss Wheelchair World periodically hosts an international meeting of women with motor disabilites from different latitudes of the world, where, through a contest of beauty and various recreational activities, celebrate the value of inclusion and feminine empowerment.

The main objectives of this initiative are: › › › › ›

a) Elimination of stereotypes and patterns of conventional beauty.

b) Make visible the causes of women with disabilities around the world and generate the collective empowerment

c) Be an institution that acts as a true change agent at an international level, generating a more empathic world with inclusion of people with disabilities, the respect for human rights, diversity and the care for biodiversity

d) Generate a world more attached to values of accessibility and universal

The First Edition was held in Waraw, Poland in 2017. Twenty-four ladies participated. The winner was Aleksandra Chichikova of Belarus.

MISS
WHEELCHAIR WORLD

Second Edition: Mexico

October 2022

Karen Pamela Rocha Ruiz

The twenty-four participants of the first edition of Miss Wheelchair World held in Warsaw, Poland, October 2017 each represented their country's values, culture and traditions with pride and dignity.

During their stay in Poland, the participants shared experiences and opinions about the importance of inclusion, and discussed ways to make our planet more aware of the needs of people with disabilities. Solid friendships were created that have endured beyond the pageant. Empowerment of women with disabilities and the value of inclusion worldwide took center stage.

As the International Director of the Miss Wheelchair World organization, *Karen Pamela Rocha Ruiz* is excited about the upcoming 2nd Edition of this international contest. Originally from Valle De La Trinidad, Ensenada, Baja California, Mexico, she is proud to be entrusted with the responsibility to head the organization for the 2022 pageant and pleased to have the event hosted in her home country at the Rosarito Beach Hotel which is the largest beachfront resort in Baja California. Since they opened their doors in 1924, it has welcomed millions of visitors, including movie stars, presidents, and international royalty. In October, 2022, it will welcome the proud participants of Miss Wheelchair World 2022.

MISS WHEELCHAIR WORLD 2022 FINALISTS

Brazil	Ana Paula de Oliveira
Cameroon	Medzuh Sojip Nicole Michele
Canada	Melissa Exton
Chile	Damaris Franchesca Carrillo Samaniego
Colombia	Viky Dayanna Monroy Hernández
Costa Rica	Vilky Yanina Sánchez Faerron
Czech Republic	Kristyna Krenova
Ecuador	Sara Cristina Llulluna
El Salvador	Karen Marlene Guzmán García
France	Magali Saby
Guatemala	María Gertrudis de León Navarrete
India	Somya Thakur
Kenya	Esther Nyakiuru Njuguna
Malaysia	Nur Ashikeen Binti Iqbal
Mexico	Karen Koch Ferrer Aquino
Mongolia	Lkhamsuren Bold
Netherlands	Tirzah Lopez
Nigeria	Rita Ofili
Panama	María de Los Ángeles Aguilar Vega
Peru	Sandy izquierdo Tafur
Poland	Anna Ploszynska
Romania	Alivia Petrea
Russia	Ayuna Berbidaeva
Spain	Silvia Arbelo Gonzalez
South Africa	Tamelyn Bock
Tanzania	Witness Raphael
Ukraine	Khrystyna Syrova Kovalyshyn

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Avi
GOLDEN

Avi is a stroke and aphasia survivor. He was an New York City paramedic and about to start medical school when he had a stroke. Prior to his stroke, he loved many outdoor sports like horseback riding, kayaking, sailing, bicycle riding, snowboarding, etc. Now, post-stroke he has aphasia (difficulty communicating) and can't use one arm, but still enjoys many of the same thrilling activities.

Avi completed his Bachelor of Science in Biology at Towson University, in Maryland, USA.

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1 AS SOMEONE WITH APHASIA, WHAT CAN YOU SHARE ABOUT THIS CONDITION THAT YOU THINK WILL HELP OTHER PEOPLE?

Everyone is different. For example, I have Broca's aphasia. There's also Global aphasia and Wernicke's aphasia, and different levels of ability or difficulties that each person may have. Working hard with a Speech Language Pathologist is very important. It may take a long time to make progress.

2 WHAT TREATMENT PROGRAM DID YOU FIND MOST HELPFUL IN YOUR PARTICULAR CASE?

I had individual therapy and then I also participated in a group. At first, I could only say the word "Michael", and it's funny now because I didn't even know anyone named Michael! It's important to socialize with others who have aphasia and have some fun, too. When a Speech Pathologist leads the group, the person with aphasia might not know they are working on communications skills when they are in that group.

3 WHAT ADVICE WOULD YOU GIVE SOMEONE WITH SEVERE APHASIA?

Don't give up. There are alternate ways to communicate if speech is very difficult. You need to trust your Speech-Language Pathologist and work with them.

4 WHAT ADVICE WOULD YOU GIVE FAMILY MEMBERS OF SOMEONE WITH APHASIA?

Families need to learn some of the best ways to help out a person with aphasia. Sometimes waiting without filling in words for them is better. The Speech Pathologist can give the best advice for each person.

5 HOW DOES APHASIA AFFECT YOUR DAILY LIFE RIGHT NOW AND WHAT TECHNOLOGIES DO YOU FIND MOST HELPFUL, IF ANY?

I have some trouble with writing. I use speech-to-text dictation software. My cell phone is a great help. When I can, I go speak to groups along with a Speech Pathologist. I have a PowerPoint presentation, and it includes pictures of me doing sports and activities you might not expect.

6 AS AN APHASIA ADVOCATE, WHAT IMPROVEMENTS WOULD YOU LIKE TO SEE IN THE HEALTH CARE SYSTEM IN YOUR COUNTRY?

It is important to educate people, especially first responders, so they can have an idea of what to expect when they see a person who has aphasia in a medical emergency. The National Aphasia Association says that about 1/3 of all strokes result in aphasia. There are 2 million people in America who have aphasia, but many people never even heard of it.

7 WHAT ARE THE COMMON MISCONCEPTIONS PEOPLE HAVE ABOUT STROKE PATIENTS WITH APHASIA?

It is not a loss of intelligence. It is a problem communicating, and people can be helped even 10 years after they first were diagnosed. Recovery and progress is different for a younger person than an older person.

8 I'LL LIKE TO ADD:

There are new studies showing that the brain can make new networks and heal, which can improve the communication ability of a person with aphasia.


Katy Neas

Katy Neas: She can teach us all a thing or two!

by Alexandra Nava-Baltimore

Spanning a powerful 30 year career, Katy Neas, the Deputy Assistant Secretary at the Office of Special Education and Rehabilitative Services (United States Department of Education), works tirelessly as she continues her plan to create a clear and strong support system for children, families, teachers, and all those involved in the education of students with and without disabilities. Using her passion and drive, along with the experience and skills she gained from her early career in Senator Harkin's office, Easterseals, and the Physical Therapy Association, Katy is a catalyst in the world of education.

[This interview has been edited for length and clarity.]

Can you share with me a bit about your family and where you grew up? What college did you attend and what was your choice of study?

"I grew up in Des Moines, Iowa. I am the middle child. I have two brothers. I had a sister who died before I was born who had multiple significant disabilities. When I was younger, my parents talked about her infrequently. Once I joined this field, I've learned a lot more about what her life was like, being medically fragile [and] what that was like from my parent's perspective, my mother's perspective, mostly. Being a family was very important to them. And there were things that we did because we were a family that was sort of the rule…why were we doing this? Well, we do this because we're a family. That certainly was a big part of shaping me in terms of my view. Family's always been the most important thing to me. My family is not just my biological family. I grew up in the family I've created but certainly the family of people I've gotten to know over the course of my career.

When I was in high school, one of my best friends committed suicide. It really rocked my world in a way, changing my perspective of needing to help people and wanting to not stand back on the sidelines, watching terrible things happen when maybe I could do something to alter that course. I certainly didn't sort of sit down and say, "I'm going to channel this pain into something good." It is just something that happened over time.

My older brother got into Georgetown. We would visit him in Washington. I thought Washington was probably the coolest place you could ever be. There was a Georgetown alumni representative in Des Moines and I had met with her several times. She suggested I apply to the School of Language and Linguistics. When you apply to the language school, you apply to a specific language. So I checked the box that said Chinese - having never studied Chinese because it was a good strategy for getting in.

So I got the letter, "Dear Miss Beh, [we are] happy to [accept you]." [When I got there] I did nothing but study. I'd go out Friday night and then I'd study all day Saturday and Sunday because I had to test every Monday morning in Chinese. I decided that studying 24 hours on the weekend was not how I wanted to spend my entire college career, so long story short, I switched majors and

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ended up leaving Georgetown with a French degree with a minor in economics. I was kind of a lost soul in the sense that I didn't really know what I wanted to do when I grew up.

Do you think your time at Georgetown helped you prepare to be an advocate for the community?

I got an internship with my congressman, who was running for Senate. When I got to his office, I finally felt like I belong[ed] somewhere. It [was] like, this feels good, I like these people [and] this work. They were fun and dedicated Iowans. It was the first time in my Georgetown career that I was like, I could do this. I liked it so much that I ended up working two days a week.

I graduated at the end of May 1985 and started working in the senator's office in July as the receptionist. Ten hours a day I answered the telephone. It was absolutely fascinating because it was during the middle of a farmer crisis. We talked to desperate farmers all day long, or old[er] people who just needed somebody to talk to. It was a great learning experience.

By the time 1987 came along, Senator Harkin was chair of the Subcommittee on The Handicapped. We changed the name to the Subcommittee on Disability Policy. Senator Harkin was the Chief Sponsor of the Americans with Disabilities Act. I was back up staff to Bobby Silverstein, our staff director. That was certainly an experience of a lifetime, to be able to work on culture-bearing change. I got to meet all the different aspects of the disability community. I met with lots of different people within the business community.

When I left Capitol Hill, I had a series of jobs. The most profound one was working at Easterseals where I was for almost 23 years, and I did public policy on behalf of kids with disabilities and their families, early education, K-12. Over the course of those 23 years, I went from one of the lobbyists to running the office.

Had I not had that job on the Hill, I never would have been

Senator Harkin and Katy Neas

at Easterseals. And if I hadn't been in Easterseals, I would never be here. I [have] been very lucky for a clueless kid who didn't know what she wanted to do when she was in college. I've been really lucky to have this magnificent career and meet these wonderful people and have the opportunity to serve. It's not by my own design, it's all been serendipity.

How did you prepare to start working in the Department of Education? My husband was very sick in 2018 and 2019 while I was working for the American Physical Therapy Association. I had left Easterseals, my daughter had gone off to college, and it was time to try something new. I am grateful beyond words for my time with the American Physical Therapy Association. When the pandemic hit, it made me think about what it is that I really want to do between Ralph's illness and the pandemic. I was getting restless and wanted to do something to serve. I had always been a Joe Biden fan. In fact, before the pandemic, I took my mom to the Iowa Caucus so she could caucus for Biden. I believed then, and believe now, that he was the person with the right temperament for what our country needs right now. So, I started talking to people who were involved in the campaign saying, "What would you think if I wanted to work for the Department of Education?" I got some positive feedback. Then it became clear that Biden would be the next president. I think for me, what was most attractive was that I had spent all this time working, mostly at Easter Seals, to see how the policies we write in Washington are actually implemented when real people are involved and what needs to happen for the policy to be meaningful.

I have helped shape the policy of the federal law, but I also was able to learn from the Easterseals affiliates that made it real for kids and families. My time at the US Department of Education is a great way to have this next chapter of my career. [The pandemic] has taken a huge toll not only on kids and families but on school systems, people who work in schools. [It] made me realize how vulnerable the whole education system is for everybody. To be a part of a group of people that wants to try to help is an honor. I feel like my whole career has prepared me for this moment. I feel the folks that I get to work with every day are just magnificent;


Ralph and Katy Neas

the career staff, the political staff, the Secretary, are very invested in helping schools be open and safe and a place where kids are learning. I've kind of been doing this for 30 years. Again, I feel very honored to have this opportunity.

Are there any projects upcoming, or projects that you've worked on that you would consider major accomplishments in your career? One of the things that is thrilling for me right now is being a part of the President's Build-Back Better Initiative [which] includes some historic investments in childcare and preschool services. When I was at Easterseals, we helped create an inclusive child care model program because many families with kids with disabilities couldn't find childcare to save their souls. There were childcare programs that were too afraid to take a kid with a disability. There were very few options. So we chose to create a new program. If we can't find it, let's build it ourselves. This model program has grown over the years. We now have this opportunity with the President's Build Back Better Initiative, where we are going to be able to increase not only the amount of childcare, but the quality of childcare so all kids can get an appropriate early education experience, whether in a childcare setting, or in a preschool setting. The way the program has been designed with my colleagues at the Department of Health, Human Services, and the Department of Education, [is] to be inclusive of children with disabilities from the start, not as an afterthought. They're not an add-on. It's how we do this right from day one.

I've been working on inclusive early education for at least 20 years. And to see that, knowing that I have shaped the dialogue that has helped inform where we are today. When the President's proposal in Congress hopefully [gets] approved, what that will mean for kids and working families is just mind-blowing. I'm very hopeful that the President's plan will become law, and we can start really working on making this real.

What are your future plans? What do you think the Department of Education in terms of serving people with disabilities, or creating more innovation or technology, will look like? The Department has a role to monitor how states oversee the implementation of the Federal Special Education Law. We are in the process of ramping up our monitoring so that states know they have a partner with us, but we expect them to meet the letter in the spirit of the law. Similarly, the Department and office I work in oversee the Vocational Rehabilitation Program, helping adults with disabilities get trained and placed in jobs appropriate for them. This is a place where we know we've got a lot of room for more innovation. It's something I'm really looking forward to digging into, in how we support the Rehabilitation Agencies to have more success in helping people be employed in their communities doing things that fit their skills.

One of the reasons I'm such a huge early education advocate is because I have seen over the course of my career the different skill sets of someone who had access to early intervention, [versus] those that didn't. By having that delay, not getting services until the K-12 world, [is] a disservice and makes it more difficult to catch up. The more we invest in early education, the better outcomes we're going to have in employment when people leave high school or whatever it is that's right for them. All learning really does begin at birth, and we need to support families to help them on their journey so that everybody can have the life that they want.

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What do you think are the biggest misconceptions about people who have a disability? How do you think we can, as a society and the people working in your field, change that? Stigma, low expectations, and not seeing people as people first. There's a place for all of us. I think one benefit of working in the disability community, as long as I have, is that everybody can make a contribution. Everybody can be successful in the community. Certainly, physical access with curb cuts and electric doors makes everybody's life easier and is beneficial, but we haven't really realized the benefit from an employment perspective. I think in a twisted way the pandemic has opened new opportunities. We're doing things today, [where] we don't have to physically be together to have this conversation. You don't have to have somebody in the office to do that job. I'm hoping that the creativity that was forced on us because of the pandemic will change our perspective of who can do what, and that we can continue to have that creativity applied to new industries so that more people can have more choices on what's right for them.

The other thing that I think is going to make a big difference is the bill that the President is signing today, the Infrastructure Bill, where green jobs, roads and bridges, [and] all of those things are going to be jobs with different layers to them. Not everybody needs to be the engineer. Somebody needs to be the guy that plants the tree, right? These jobs are going to have such a wide range of goals resulting in the creation of new jobs for people with different skill sets. I'm very hopeful that this is really a major turn in our employment opportunities for people with disabilities.

Why do you think it's important for society to consider inclusion and inclusivity when thinking about jobs or leadership roles, and companies hiring people? As an able-bodied middle-class, white woman, over 50, I have learned in my career that we are individually better off when we can collaborate with someone who is different from us. Hands down, no contest. We all bring the stories of our upbringing with us, we all have different experiences that shape us. I think having genuine, authentic experiences shaped how we make policy, how we think about the implementation of policy. Without that diversity, the policy just isn't that good. It's not as good as if it was informed by these different perspectives.

Who has been your role model or inspiration throughout your career? Has anyone shaped you or guided you in the work that you have been a part of? There have been a number of both personal and professional role models. Certainly, Senator Harkin helped launch me and without him, I wouldn't be sitting here. I'm just profoundly grateful for the opportunity to have been able to learn so much [from him]. When I worked in the Senate, Bobby Silverstein was my boss, and now my dear friend. One of the things Bobby taught me was you can never be over-prepared, do your homework, and always treat people with respect.

My parents and especially my mother [too] who just turned 90. She's had some health challenges and just moved into assisted living. Her vision and hearing are not great now and she's now walking with a walker. But man, she has rolled with what life has thrown at her and [has] always come out with her head up and lipstick on. She is creative and smart, there's not anything she couldn't do. Her confidence in who she is and her personal strength are things that make me proud of her every day. She's been an awesome role model over these 58 years.

Is there anything else that you want people to know about your work on behalf of people with disabilities in the Department of Education? I'm so lucky to be able to work for Secretary Cardona and President Biden, I really think that this Administration wants to partner with all Americans to try to make things better. When the President discusses Build Back Better, he really means it. Our schools get to have the support that they need. So teachers are adequately supported, both financially and with resources where kids and families feel like school and their communities are a place that welcomes them. To be a part of that strong desire to help Americans and especially Americans with young children have the opportunities that they want for themselves so that their children can grow up and be productive contributors to their community.

We are all one-car accident or one major health crisis away from needing those supports ourselves, and you never know when you're going to need them. I think we as neighbors, friends and their families, need to help create that community where everybody can be successful.

How do we create a foundation, so people can soar and people can do what they want to do, and have the opportunity to figure it out, and then to act on what it is that they want to do? I think that's part of our role here at the Department is to create those support systems. That's what I'm hoping we can do over the next four to eight years. That's what gets me out of bed in the morning – how can we make the system strong so everybody can be successful?

> **". . . There's a place for all of us. I think one benefit of working in the disability community, as long as I have, is that everybody can make a contribution. Everybody can be successful in the community."**

All photos courtesy of The Shalva Band

The Shalva Band

The word 'Shalva' means 'peace of mind' or 'serenity' in Hebrew.

The Shalva Band, based in Israel, consists of members who represent a variety of intellectual developmental disabilities and physical impairments. The Band members' disabilities include blindness, Down syndrome, and Williams syndrome.

The Shalva Band was established in 2005 and has been in existence for nearly sixteen years. It began when the director of the band, Shai Ben-Shushan suggested the idea to the founder of Shalva, Kalman Samuels. Shai did not have any previous involvement in the Shalva organization or working with people with disabilities; however, he, like the organization's founder, had a personal promise to fulfill. In 2005 Shai had recently recovered from a serious injury from his service in one of the IDF's elite units. He was injured in a complex military mission in which his commander was killed and several other soldiers were severely injured. Shai found himself undergoing several surgeries and rehabilitative treatments and personally struggling with the physical limitations that an individual with disabilities might experience. Once fully recovered, Shai decided that he would give back to the community by sharing his love and talent for music with children with disabilities.

He formally began the Shalva Band as a component of Shalva's music therapy program. Gradually, the band became an entity of its own and a social enterprise of the organization.

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Ambassadors for change . . . .

The Shalva Band hopes that with each performance the world will become a more accepting and inclusive place. By recognizing the Shalva Band's ability to create beautiful and meaningful music, audiences are essentially realizing their own ability to regard people with disabilities as respected, equal, and contributing members of society. Here are comments from some band members:

Yosef (DRUMS):
For me, being a member of the Shalva Band is being part of a family. It is a source of pride. I love to play music and make other people happy. I really enjoy what I'm doing.

Tal (PERCUSSION):
The Shalva Band is like a family to me. We've been together for many years. I really enjoy playing music with the band and getting together with everyone.

Yair (RAP AND PERCUSSIONS):
To me the Shalva Band means friends for life; its good laughs, fun, and music. I love the other band members and enjoy being with them.

Sara (GUITAR):
The Shalva Band members are my best friends. They are with me in the good and the bad, on good days and on less good days. When we are all together it is extremely powerful and an inspiration to anyone who sees us.

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The two vocalists, **Anael Khalifa** and **Dina Samteh**'s amazing voices brings listeners to tears during their performances. Here are their thoughts about being on stage and using their voice to inspire change while bringing to the forefront of people's minds the fact that having a disability should not hinder you from pursuing your passion.

Anael: The Shalva Band is like a family to me. It is my second home. We are together a lot and being a member of the Shalva Band is like being a member of a family- with all of the emotions that it entails.

I love music and it is therapeutic for me; I feel that it protects me and saves me.

When I stand on stage in front of a large audience, my goal is to make people enjoy music and to be moved. If people see in me a meaningful message or a source of inspiration, I consider that to be very valuable.

Dinah: The Shalva Band is the center of my world. The band gives me lots of confidence, good friends, and family.

I really enjoy music because music allows me to experience different worlds, to be exposed, to be moved.

When I am standing on a stage before so many people I feel a very personal sense of pride. Everyone can achieve if he wills it- it's not just a cliché. Everything is possible. This is exactly what happened to the Shalva Band.

The Shalva Band performs by invitation on stages across Israel and around the world. All of their performances are memorable but one in particular profoundly touched the hearts of listeners all over the world - their soulful, emotionally-stirring, unforgettable performance of *A Million Dreams* at Eurovision 2019.

To find out about upcoming performances, contact the band through their website or follow them on Facebook or Instagram.

www.shalva.band

The Shalva National Center

The Shalva National Center is one of the largest centers for disability care and inclusion in the world. The center was officially opened in September 2016 in response to a growing need for advanced rehabilitative services for individuals with disabilities and in recognition of Shalva's pioneering program development in this field. The campus includes an expansive inclusive playground and a main building which is 200,000 square feet in size. Each of the eleven stories of the Shalva National Center serves Shalva's different programs. As such, the center has some of the largest and most advanced disability accessible facilities; including an inclusive sports complex with a hydrotherapy swimming pool, a semi-Olympic swimming pool, gymnasium, and fitness room. The center also has facilities which are open to the public; such as an auditorium, seminar rooms, and a café. In addition to housing Shalva's rehabilitative programs, the center is an inclusive workplace and adults with disabilities work in many of the facilities. The building was intentionally designed to serve as a natural hub of inclusive interaction which is manifest in the ongoing daily activities as well as the building's unique and beautiful interior design. In times of national crisis, the Shalva National Center serves as Israel's national emergency center for people with disabilities and can host up to 1,200 individuals in disability accessible safe rooms.

Shalva was founded in 1990 by **Kalman and Malki Samuels**, whose son, Yossi was rendered blind and deaf, among other challenges, following an injury during his early infancy. At the age of eight, Yossi experienced a communication breakthrough and the Samuels fulfilled their promise to help families with similar challenges by founding Shalva.

Upon the organization's inception, Shalva's original and mainstay program, the ***After School Activity Center,*** immediately filled a gaping void in rehabilitative opportunities for children with disabilities in Israel. Over the years, as the program developed to include ***individual and group therapies, summer camps, music bands, and sports teams; parallel respite and family support components*** became organizational staples as well.

Shalva continued to establish a host of ***early intervention rehabilitative and educational programs,*** offering a holistic continuum of ***disability services from infancy to adulthood***.

Shalva has been distinguished with several prizes and endorsements; including the ***Ruderman Prize for Inclusion,*** the ***President of Israel's Prize for Excellence***, and the ***Knesset Speaker's Quality of Life Prize.*** In 2018, Shalva was awarded ***consultative status to the United Nations,*** distinguished to provide consultation and guidance on disability issues.

Shalva's management standards continue to be recognized by the ***ISO 9001/2008 certification and Midot's Seal for Outstanding Effectiveness***. Through over thirty years of partnerships with government ministries, corporations, academic institutions, social development groups, and communities worldwide; Shalva continues to successfully infuse disability inclusion into public policy, cultural platforms, and social discourse.

Of the many programs and services offered, the most utilized is ***Shalva's Me and My Mommy program***, a unique early intervention program for infant with disabilities and their parents. The program provides rehabilitative therapies and support services to 120 new babies and their parents every year. While this is not Shalva's largest program, it is the most utilized because people travel from across Israel to attend the program and the majority of infants born with Down syndrome in Israel every year begin their journey at Shalva.

The Shalva Band is a product of the Shalva organization.

The Band members' musical talents were discovered and developed within Shalva's music therapy programs when they participated in Shalva's rehabilitative programs as children. Today, the Shalva Band has a recording studio at the Shalva National Center where they often practice between performances.

www.shalva.org

What is adaptive clothing and how can it make life easier for people with a disability?

Have you ever tried to do up a zip or button a shirt one-handed? Put on a pair of jeans while seated? Do you know someone with Autism Spectrum Disorder, who can't stand the feeling of certain fabrics against their skin? If your feet are different sizes, or you only have one foot, how do you buy shoes?
Advances in "adaptive clothing" aim to address these problems.

Adaptive clothes are specially designed for people with a disability. This can mean providing one-handed zippers on shoes, replacing buttons with magnetic closures or designing clothing and footwear so you can get dressed while in a seated position.

The key to effective adaptive clothing is catering for the vast array of needs different consumers have, while maintaining style and fashionability. Recently, fashion brands have begun to provide on-trend clothing with new styles, combining fashion and technology for people with a variety of disabilities.

Here are five different ways fashion is approaching adaptive clothing.

1. Magnets, not buttons

Under Armour were one of the first to adopt a magnetic zipper in clothing. Their redesigned jacket zip called MagZip uses magnets to connect the ends of the zip, making clothing easier to do up one-handed.

Magnets have also been used in shirts, pants and other garments in lieu of buttons. These enable individuals who don't have the dexterity or ability to use buttons to better dress themselves.

2. Shoes without laces

Different iterations of shoes also aim to make the process of tying laces easier, or remove the need all together. Zips can replace traditional laces, enabling shoes to be done up one-handed.

Another design is Nike's Go FlyEase, a sneaker utilising a hinge design. The wearer steps into the shoe and the hinge opens, holding the shoe in place.

The first FlyEase shoes proved popular with a wider audience, creating supply issues and a large resale market. This shoe is an example of Universal Design – a principle which proposes products should be designed in such a way that anybody can use them.

3. Clothing for the wearer

Many people with autism are sensitive to certain fabrics or to tags and clothing labels.

Adaptive brands, such as JAM the Label screen-print labels, avoiding physical tags and offer a range of hyposensitive bamboo and linen fabrics.

Baby onesies and traditional bathers which cover the stomach are not always practical for everyone. Their design can be restrictive to people who are tube feed or use ostomy pouches.

Among other designs, Australian adaptive clothing manufacturer Wonsie sells garments with stomach access for both children and adults who require frequent access to the stomach, meaning medical devices need not be a barrier to fashion.

4. 3D printing and custom designs

In the past, adaptive products were often designed to be unobtrusive, such as black wheelchairs or flesh-coloured prostheses and hearing aids. But this is changing too.

3D printing and advanced manufacturing are allowing for great flexibility and customised designs of various devices and fashion items.

Open Bionics used 3D printing to create the Hero Arm bionic arm powered by muscle movements.

By using 3D printing to customise the arm to the user, the company is also able to provide users options around designs ranging from colours to branded content: a blend of function and fashion.

5. Unique sales platforms

The technology behind adaptive fashion is not limited to product design: it is also used in sales and marketing, too.

Every Human's Unpaired system allows consumers to purchase single shoes, while searching by size, width and a range of adaptive features such as easy to put on, and friendly for those who are wearing ankle/foot orthosis.

This can benefit people who have different sized or shaped feet or with prosthetics, where traditional shoes would not suit.

While it seems like a relatively simple idea, this requires brands to have more sophisticated ordering systems. Products must be itemised individually, rather than in traditional pairs, and tagged with additional features such as left or right shoe, and which adaptive features each side possesses, so consumers can search by their needs.

Adapting beyond technology

Like many consumers, people with a disability simply want to be able to shop in physical or online stores and find clothing they like and that fits. So while technology is helping retailers offer an increasing range of adaptive clothing, it is not the only solution.

The next step is to not only think about the clothing itself, but also about the wearer and how they want to shop.

All fashion brands should be adapting their items to the vast array of consumer needs: the technology is already here.

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Massiraa, Dubai

Marco Pasqua, Canada

BUSINESSES OWNED BY PEOPLE WITH DISABILITIES

Colletey's Cookies, USA

www.retrophiliac.etsy.com, USA

CERTIFICATION COURSES

Rick Hansen Foundation Accessibility Certification, Canada

DISABILITY-SERVING ORGANIZATIONS

Access Israel, Israel

Easter Seals, Canada

Easterseals, USA

FONHARE, Haiti

Friends of Access Israel, USA

The American Association of People with Disabilities, USA

The Arc, USA

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Accessible Media Inc., Canada

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Paratrek, Israel

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Accessible Indonesia, Indonesia

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> "TravelAbility was a huge stepping stone for the disability community but the real impact I saw was in the industry – and that’s exactly where it needs to be. You brought together strangers who all have a common goal of universal access in an industry that all people, regardless of limitations, want to be a part of."
>
> — Eric Lipp, Founder, Open Doors Organization