CN Vision Image Consulting Goes To 2019 Level Up Conference

CAPTIVATING! Wins AWARD
Disclaimer

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EDITOR'S NOTE

AWARD-WINNING MAGAZINE!!

That’s right! Only eight months in the making and CAPTIVATING! has received its first award from the Texas Rehabilitation Association (TRA).

This special edition of CAPTIVATING! is a combination of July/August issues. In this special edition we share news of our award, invite you to meet the team behind our magazine, and an exciting opportunity our co-founders recently experienced.

Over the past seven months CAPTIVATING! has accrued virtual team members and contributors who not only span the world, we also share a deep passion for about bringing more understanding, compassion, and inclusion to our communities. Being honored with a TRA 2019 Award for our efforts in the representation of people with disabilities in journalism validates our work.

Among the content being offered in this edition, we want to make you aware of an important “Rural Safety and Resilience” research study by Kimberly Aguillard. The study is open to women with disabilities who’ve experienced violence in rural communities. The results of the study will be used to improve and strengthen programs and policies to serve women with disabilities who have experienced violence. Study participants will be compensated with a gift card for their time and expertise.

This month’s guests include Holly Tuke, Jessica Goodwin, and Jessica Loomer. Holly and Jessica Goodwin took matters into their own hands to increase awareness on accessibility issues for people with disabilities at live entertainment venues. Jessica Loomer, who lost her sight to Leber’s hereditary optic neuropathy (LHON) tells us how she was able to resume her passion for running. You’ll also want to check out Catherine Boldt’s review of the film “Five Feet Apart.” Keep an eye out on our Instagram account for a GIVEAWAY.

July Awareness
- Group B Strep Awareness Month
- Disability Pride Month
- 26th - Disability Independence Day
- 30th - Gastroschisis Day

August Awareness
- 5th Year Anniversary of ALS Ice Bucket Challenge
- 7th Purple Heart Day
- 26th Women’s Equality Day

We hope you enjoy this issue of CAPTIVATING! Magazine. We invite you to submit questions, articles, and ideas to editor@captivatingmagazine.com or through our website at www.captivatingmagazine.com.

CAPTIVATING! "The power and possibilities of inclusion are limitless"
MEET THE CAPTIVATING! TEAM

Includes headshots of CAPTIVATING! Team members along with their role and a brief bio.

JUAN ALCAZAR, Filmmaker

Juan Alcazar is a legally blind filmmaker/YouTuber. He attended film school at San Francisco State University. His YouTube channel JC5 Productions focuses on telling stories through films or personal videos. His channel also focuses on visual impairment and disability with the goal of showing that everyone has stories to tell no matter what their limitations are.

CATHERINE BOLDT, Media Reviewer

Catherine Boldt has spent her adult life being a disability advocate. She is a designer and works in the Education Outreach Department and provides accessible tours at Taliesin, Frank Lloyd Wright's Estate. She is a past President of The Canadian Research Institute For The Advancement of Women, where she presided over an International conference on Women with Disabilities and initiated a national essay contest and book called "That Body Image Thing".

VICTORIA CLAIRE, Resident Artist

Victoria Claire is a registered blind Professional Artist in Contemporary Sculpture, Public Speaker, Retina UK Ambassador, Writer, Musician, Sight loss Mentor, and Advocate. Based in the UK her artistic career spans 25 years, her work is owned all over the world. As an inspirational speaker, she shares her journey of sight loss and the beauty within blindness, proving that with a positive mindset, an openness to adaptivity and accessibility a wonderful life is there for the taking, full of success, achievement, and joy.

JENNIFER DUTROW, Fitness Expert

Jennifer is a retinitis pigmentosa warrior who found her post-diagnosis purpose in helping others. She is an advocate for fitness and finding one’s own way through life, no matter what that may look like. "Sometimes the most beautiful path is the one you’re not meant to see, but to feel.”
MARTHA HARRIS, Accessibility Consultant

Martha was born in Paraguay, lived in Baltimore, grew up in a small town in Pennsylvania went to grad school in Louisiana, and now lives in Minneapolis. Her undergrad degrees are journalism and sociology. She studied for a Masters in teaching blind students, worked on an adult literacy certificate, and took online courses to learn about web and app accessibility. A former teacher, Martha is currently a web accessibility tester.

REV. REBECCA L. HOLLAND, Staff Writer

Rev. Rebecca L. Holland is a Filipino American pastor in the United Methodist Church and an author with low vision. She is the chair of the Disability Ministries Task Force of the Susquehanna Conference. Through her writing, she works to make the church and the world more accessible for people with disabilities. Her book, HOPE FOR THE BROKEN, is coming soon from Touch Point Faith.

BEATRIZ GARCÍA MARTÍN, Accessibility Travel Editor

Beatriz is a visually impaired woman and a travel blogger who loves to explore new places. She holds a master's degree in Communication and works in a Foundation promoting job's opportunities for people with disability. Losing her sight due to Retinitis Pigmentosa, she chooses to enjoy and share her passion for traveling now. You can follow her adventures in theblindcanegirl.com.

CARRIE MORALES, Accessibility & Technology Consultant

Carrie Morales was born legally blind with aniridia (complete or partial absence of the iris) and glaucoma. She used to work at a Low Vision Center, giving demos and helping clients find the right assistive tools and technology. Now, she has a website (www.liveaccessible.com) and youtube channel dedicated to helping people “Live Accessible”. With her husband who is totally blind, they want to share the message that “Blindness or low vision does not limit or define you.”

STACY FLYNN, PT, DPT, CWS

For most of her Physical Therapy career Stacy Flynn worked at the VA Hospital in Houston and loved working with the Veteran population. She is the author of “Experiencing Life After Limb Loss: A Guide for Patients and Families” which can be found on Amazon. She currently works as Adjunct Faculty at Texas Woman’s University and has her own consulting company Serenity Physical Therapy Education & Consulting. You can contact Dr. Flynn with questions or comments at SerenityPTEC@gmail.com.
As co-founders of CAPTIVATING! when Chelsea and I began this project, we believed we could change the world by connecting and enlightening people of all abilities. We are extremely fortunate that we’ve been able to gather together a group of like-minded passionate individuals who have spent many volunteer hours working to promote the abilities of those within the disability community. Because we strongly believe in the value of people with disabilities, we extend our heartfelt thanks to our team who provides their time, talents, and content for the betterment of all people.
On Thursday, July 18, 2019, at the Drury Plaza Hotel, the co-founders of CAPTIVATING! Magazine, Stephanae McCoy and Chelsea Nguyen received the 2019 Texas Rehabilitation Association (TRA) Award on behalf of the entire team of CAPTIVATING! The magazine was chosen to receive the TRA award for their efforts to promote the representation of people with disabilities in journalism.
The goal of CAPTIVATING! magazine is to bring more understanding, compassion, and inclusion to our communities by connecting and enlightening people of all abilities. The 2019 Texas Rehabilitation Association (TRA) Annual Conference, “Navigating the Rivers of Change,” was held in San Antonio, Texas from July 17-19. All honorees were recognized at the luncheon on Thursday, July 18 at the Drury Plaza Hotel. Chelsea Nguyen, one of the co-founders of CAPTIVATING!, is also the president of the Houston Area Rehabilitation Association. While Nguyen and McCoy each received individual awards inscribed with their names, they made certain to accept the award on behalf of the entire CAPTIVATING! team. Chelsea mentioned each team member by name in her acceptance speech (For more information about the CAPTIVATING! team, please be sure to check out this month’s the “Meet the Team,” article!).

“Receiving an award for what we do to better the lives of people of all abilities is such an honor and we are truly grateful and humbled by it,” said Nguyen. “We couldn’t do any of this without our phenomenal team who shares our passion for accessibility, inclusion, and representation.”

When Nguyen and McCoy began the project that would become CAPTIVATING! Magazine, they did so because they believed that they could change the world by connecting and enlightening people of all abilities. “We are extremely fortunate that we’ve been able to gather together a group of like-minded passionate individuals who have spent many volunteer hours working to promote the abilities of those within the disability community,” said McCoy.

Since CAPTIVATING! magazine was founded eight months ago, the publication has reached readers across the world. CAPTIVATING! has helped to form connections across countries and communities by raising awareness and strengthening ties within the disability community. CAPTIVATING! is an entirely volunteer-based effort and one of the most inspiring things is the way that people with and without disabilities have utilized modern technology in order to create a publication that is raising awareness and changing lives. Although the entire team has never gathered in person, they continue to produce content that makes an impact. In many ways, technology has become the great equalizer for people of all ability levels and CAPTIVATING! magazine is showing the world that people with disabilities can be talented professionals and artists.

“Because we strongly believe in the value of people with disabilities, we provide our time, talents, and content free of charge,” said McCoy. “We do this for the betterment of all people and to get our message out to the world.” The team at CAPTIVATING! is helping to show the world that the possibilities for people with disabilities are truly limitless!

Image Descriptions: 1) The header image is a photo of the 2 awards. They are oval shaped glass on a wooden base and say: “Texas Rehabilitation 2019 Special Project Award”. 2) In this photo, Chelsea is holding her award and standing with Rachita Sharma, TRA President and two other fellow Awardees Nicole Rideau (recipient of Marilyn Padgett Extra Mile Award) and Robert Cox (recipient of the Legislative Award). 3) Chelsea is holding her award and standing with another Houstonian, Karen Stanfill, TRA member, and Chelsea’s Secretary, on the Houston Area Rehabilitation Association which is a subchapter of the TRA.

To provide exemplary leadership through social advocacy and legislation, advance cultural awareness and competence across communities, promote excellence in research and practice, and support professionals engaged in the employment and independence of individuals with disabilities.

~NATIONAL REHABILITATION ASSOCIATION MISSION STATEMENT
After 18 months, numerous specialists, and countless tests, Sunny Brous was diagnosed with amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig’s disease. It seems inconceivable that something as insignificant as a twitching ring finger could end with such devastating results. However, for Sunny, who was 27 at the time of her diagnosis, living with ALS became her reality.

Ironically, the motivation that drove Sunny to her doctor wasn’t the tremor in her finger but pain from a pinched nerve in her back. Since she was in the right age and gender demographics for multiple sclerosis, Sunny’s doctor ordered a CAT scan to rule this out. The search for answers eventually led Sunny to an interesting conversation with a pain management spine specialist. His question to her was simple: “why did you come to get injections in your spine?” This appointment ended with Sunny being referred back to her general practitioner.

Starting over from the mindset that her condition was autoimmune, Sunny’s doctor made a referral to a neurologist. The neurologist narrowed it down to ALS or something that mimics ALS and while Sunny would again be referred to someone else this time it would be different.

In December 2014, she met with Dr. Philip at Texas Neurology in Dallas. On January 20, 2015, about two weeks before her 28th birthday, and all alone at her appointment, Sunny received the earth-shattering diagnosis of ALS.

I WAS ALONE IN THAT ROOM AT 27 BEING TOLD I HAVE A TERMINAL, LIFE-ALTERING, CONDITION.

While Sunny would again be referred to someone else this time it would be different.

In December 2014, she met with Dr. Philip at Texas Neurology in Dallas. On January 20, 2015, about two weeks before her 28th birthday, and all alone at her appointment, Sunny received the earth-shattering diagnosis of ALS.

IT IS A DISEASE THAT IS ABSOLUTE TORTURE FOR THE PERSON GOING THROUGH IT AND FOR FAMILY AND FRIENDS WHO HAVE TO SACRIFICE THEIR ROLE AS A LOVED ONE AND STEP INTO THE ROLE OF CAREGIVER. ~SUNNY BROUS

UPDATE: Originally published in the May edition of CAPTIVATING! We are republishing this article in recognition of the 5th Anniversary of the ALS Bucket Challenge. Sunny’s story has also been featured in the June edition of People Magazine.
After delivering the blow that would change the course of Sunny’s life, the Dr. Philip asked her three questions:

- Do you want to participate in clinical trials?
- Do you want to seek a second opinion?
- Do you want to go on riluzole? (which at the time was the only FDA approved drug to slow the progression of ALS)

Sunny answered yes to all three questions but she wanted to know why—if there was an FDA approved drug on the market—wouldn’t people choose this option. Dr. Philip explained that because of the cost of the medication and the short life expectancy, many people chose to invest their remaining time and money in their families.

Thankfully for Sunny, her insurance covered the medication and it only cost her a $10 co-pay. Even so, we were struck by Sunny’s amazing compassion when she went to drop off her prescription in this scenario told in her own words:

I went to Walgreens dropped off the prescription and the pharmacy tech said “I’m sorry but we don’t have this medicine in stock but I can order it for you and it should be in by tomorrow” and I just started crying. And she was like “I’m so sorry, this happens sometimes, this isn’t a common drug,” and I was like no, no, no, no, these are tears of joy that this disease isn’t so common that that medication is in stock like this isn’t something you just keep on the counter for just in case.

After listening to Sunny explain everything she went through to obtain her diagnosis, we asked her exactly what is ALS and what does it do to a person affected by it?

Sunny told us that the disease is a malnourishment of the muscles which causes them to harden. The way it begins is either limb onset meaning it starts in your hands or your legs or bulbar onset which means it starts in your mouth or your throat.

ALS only affects a person’s voluntary muscles and the way Sunny explained it “even though you don’t have to tell yourself to breathe you can stop yourself from breathing so it’s considered a voluntary muscle.” As the connections from the brain to the muscles are broken down, the muscles begin to atrophy because they’re not getting used. Eventually, the muscles waste away as the disease continues moving throughout the body. Since the body is moving into a permanent state of paralysis a person begins to develop respiratory-related issues. As ALS progresses the ability to swallow and even to fully extend the diaphragm are decreased. The likelihood of developing pneumonia or getting to the point where you aren’t taking in enough oxygen to offset your output essentially means drowning in carbon dioxide.

Despite Sunny’s prognosis, like her name, she is a beautiful and vibrant woman who works hard to increase awareness of ALS as its research is severely underfunded. It should be noted that there is no known cause for this disease and it can happen to anyone at any given point in their lives. To learn more about Sunny’s story you can watch our interview at this link.

To connect with Sunny you can follow her blog at www.sunnystrong.com.

Image Descriptions: 1) Like her name, Sunny is beaming with a beautiful smile, posed standing near a pool at her in-laws home. She’s wearing a lavender long-sleeved top with a crew neck. Her shoulder-length hair has golden highlights. 2) An outdoor shot of Sunny and her husband wearing the Sunny Strong.com t-shirts with an image of a sunflower on them. There is an ALS red banner behind them.
According to a report done by RTI, because of the Ice Bucket Challenge, the ALS Association was able to increase our annual funding of research around the world by a staggering 187%—committing nearly $90 million around the world in research funding between 2014 and 2018. And since then we’ve been able to make major scientific advances (like discovering 5 new genes), expand care for those living with ALS.

In 2014, two men with ALS took it upon themselves to make a statement with simply a bucket, ice, and water. What started as a simple challenge quickly became a major movement that shed light on an often-overlooked disease. Not only did the Ice Bucket Challenge spread awareness about ALS across the globe, it also generated $115 million for the ALS Association. There was nothing like the challenge before, and nothing like it since in terms of virality for a medical cause.
Locally, the Ice Bucket Challenge had a tremendous impact on The ALS Association Texas Chapter and has enabled us to expand our services across the state. As a result of the challenge, we’ve been able to provide $300,000 in financial assistance to people with ALS and their families, established eight new clinic partnerships to provide crucial multidisciplinary care for patients, and have connected with 1,530 new people with ALS since 2014. We’ve also been able to improve our equipment inventory in our loan closet, to ensure more people with ALS have access to the equipment they need without the financial burden.

We’ve made so many strides since 2014 and we couldn’t have done any of this without your help! The Ice Bucket Challenge was unlike any other social media movement in terms of spreading awareness for a disease and we’re so grateful for each and every person who participated and for everyone who continues to advocate for those with ALS.

The ALS Association is committed to providing transparency and painting a clear picture of our fund-allocation. If you’d like to see how money raised from the Ice Bucket Challenge has been used take a look at our ALS Ice Bucket Challenge Commitments page. Interested in diving deeper into the progress we’ve made? Read the report and learn more about the impact of the Ice Bucket Challenge here. The Ice Bucket Challenge has been used take a look at our ALS Ice Bucket Challenge Commitments page. Interested in diving deeper into the progress we’ve made? Read the report and learn more about the impact of the Ice Bucket Challenge here.

**Image Descriptions:**
1) A large group of people participating in the Ice Bucket Challenge. They are dumping cold water on themselves from orange and blue buckets. 2) A still shot of Sunny Brous taking the challenge. Photo is from www.alstexas.org 5 year Ice Bucket Challenge compilation video.

“Five years after the Ice Bucket Challenge soaked the world, the pace of discovery has increased tremendously, bringing ALS researchers closer than they have ever been to real breakthroughs in diagnosing, treating, and eventually curing this disease.

~Calaneet Balas, president and CEO of The ALS Association.

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Access For Us is a non-profit blog that aims to raise awareness on the lack of access at venues that show live entertainment (concerts, theatre, festivals, and more). Having met through their love of music, and Jessie J in 2014, Access For Us was founded by disability and lifestyle blogger Holly Tuke and photographer Jessica Goodwin.

WHERE DID IT ALL BEGIN?
Holly is registered as blind due to a condition called Retinopathy of Prematurity (ROP) as she was born at 24 weeks. She has no useful vision but doesn’t let this stop her from going to gigs. Jessica has a passion for equality of all kinds, and due to the experience of attending live events with Holly, has experienced the quality or lack there-off surrounding accessibility from a sighted person's point of view – this having inspired her to get involved and help as much as possible.
Holly has had some bad and difficult experiences of getting VIP/meet and greet packages for Jessie J and Shawn Mendes. These experiences, in particular, grew Holly’s determination to raise awareness around the struggles that disabled fans face. They both actually missed out on meeting Jessie J back in 2017 because of the lack of disabled access for the VIP upgrade.

After experiencing front-row at a Jessie J gig together back in November 2018, this is when Access For Us was evolved. Holly and Jess wanted to speak out, raise awareness and tackle the issues that disabled people face when attending concerts, festivals, theatre shows and such other events.

WHAT DO WE AIM TO ACHIEVE?
Thanks to fans sharing their stories, Access For Us hopes to create change towards the lack of accessibility at venues across the UK, and via online ticket systems. Access For Us was originally going to have a focus on live music, but there are also issues in other areas of entertainment, so it was branched out and made even bigger.

By sharing fans stories, the main aim is to raise awareness of the issues that disabled fans face and highlight what needs to be done, in order for disabled fans to have equal access to live music, theatre shows, and other events. But it’s not all about bad experiences, the good experiences are just as important. Let’s shout about good experiences as well – a venue that has brilliant disabled access or goes above and beyond to accommodate your needs, or how easy and stress-free it was to purchase disabled access tickets for a particular event.

Access For Us wouldn’t be what it is without your experiences... Let’s start a conversation that will hopefully create change. Access For Us is looking for contributors, you can either share your experiences by writing a blog post or the team can come up with a series of questions that you can answer in a written interview. When it comes to the type of experience it really doesn’t matter what it is, we want to know because we want to help, and we need to make venues and their managers, aware of these issues.

If you’re interested in sharing your experience with the Access For Us team then we would love to hear from you! Get in contact by sending an email to: info@accessforus.com or by messaging us on Facebook, Twitter or Instagram and we will get back to you as soon as we can. If you have got an event coming up then keep the conversation going on social media using the hashtag #AccessForUs.

Website: accessforus.com
Facebook: www.facebook.com/accessforusuk
Twitter: twitter.com/accessForUsUK
Instagram: www.instagram.com/AccessForUsUK/

“Let’s shout about good experiences as well – a venue that has brilliant disabled access or goes above and beyond to accommodate your needs, or how easy and stress-free it was to purchase disabled access tickets for a particular event.”

Image Descriptions: 1) The header image was taken from the Access For Us poster. The image contains multi-coloured shapes in the background which are meant to represent stage lights. Behind these is a black backdrop, they combine together to make the full background. 8 symbols relating to disability - hearing aid, inhaler, a ribbon with a person's face outlined, a puzzle piece, wheelchair, person wearing glasses and using a cane, brain and a ribbon next to half a butterfly. At the bottom are Holly and Jessica’s logos. 2) Blue tinted black & white photo of a crowd at a concert with arms raised.
The ad on the radio fairly screamed, “Beat the heat this summer.” How exactly are we going to do that? Answer: We aren’t, but we can live with it. As I sit at my writing table I can think of several things to do about summer or year ’round in tropical areas. I’ll do these randomly off the top of my hatless head. (I don’t wear my hat in the house, which, by the way, is nicely air-conditioned.)

As we enter July, much of the Northern Hemisphere will experience several weeks of hot temperatures and bright sun. For anyone with a neurological disease such as multiple sclerosis or fibromyalgia, the summer heat means fatigue is a problem. For those with light skin, sunburn is a serious matter. Let us not forget that darker skin can burn, as well. Para and quadriplegics who do not regulate heat in the paralyzed areas face the serious danger of over-heating.

I personally do better in the heat than the cold, but I still have to manage it. Along the way, I’ve read some very good tips and learned a few on my own, sometimes the hard way.

These are some things that come to mind in no particular order that can help. The byword of summer is Hydrate. Hydrate, hydrate. I can’t say it enough. Water is generally considered the perfect hydration drink. I like my water either filtered or natural spring water and cold. I cannot comment on sports drinks with any authority. If I get too hot, I like a couple of them. Please note that energy drinks are not considered hydration drinks.

A simple, yet effective, tool for keeping cooler and reducing light is the hat. There are hats of all styles. For light and heat, we are concerned with three things: the color, the brim, and the material.
Lighter colors reflect light and heat. A white hat will let less heat get to the head than a black one. A dark color on the underside of the brim, however, will help with light that is reflected off of sidewalks and bright surfaces.

Brim can be wide (think summer straw hat), turned down (rain hat), or just in front (baseball cap). Wider deflects light off of a wider skin area, whilst turned down offers good protection for the sensitive skin on top of the ears. The ubiquitous baseball cap is practical, relatively inexpensive, and comes in a myriad of logos. A friend who was helping me clean out my closet asked, “How many of those hats do you really need?”

Material speaks for itself. A light cotton will be cooler than wool or felt. I have a cooling hat that has a wide brim, dark green underneath, and looks silly (my wife disagrees about silly). It can make my day outside possible.

Much the same can be said for clothing. Light colors reflect light and thus heat. Before moving to Florida I’d never have teamed a white shirt with khaki pants or shorts. It is common, and I quickly found out why. Fabrics that breathe are cooler, and looser is also cooler.

I know this will give you the perfect excuse to go out and buy that white Porsche you’ve been wanting. The color of your car makes a huge difference to its interior temperature. When we come out of the grocery a black car in the Florida sun will be 40 degrees (22C, I think) hotter than a white car. Either way, it is best to air it out and let cooler, fresher airflow through before getting in. Please don’t ever leave children or pets in the car.

Lighter to reflect light, dark to keep it out of our eyes, fresh air, and water. Now go find a nice air-conditioned spot and get back to the book you’re reading!

How do you keep cool in summer? Let’s share ideas and things that work for each of us.

And that photo at the very top? That was the actual color of a Caribbean sunset, not a filter. The day got very hot. Thank you for stopping by. I hope I’ve not sounded too much like a physics professor, except maybe my high school physics teacher who made even physics fun.

Picture Descriptions: Top photo shows a hot, hazy sunset. The white sun is setting below a cloud bank is an orange sky. The second photo shows a screenshot from a phone showing the weather forecast. Currently 94 degrees. The forecast for 3 days is for sun and thunderstorms with highs in the 90’s. There is a notation written on it, pointing to the 94 that says, “34C.” The third photo has my wife Sandy wearing a soft blue and white striped hat with a large, floppy brim. She has on a matching top, dark sunglasses, and has long light-colored hair.
About a week ago, I volunteered for the first time with lots of other wonderful volunteers at #TexasAdaptiveAquatics (TAA). We learned how to help disabled children, adults and returning wounded and disabled Veterans how to safely transfer from a wet wheelchair into submerged adaptive water skis. They could then experience Sit-Skiing with a Side Skier while other volunteers steered the boat safely around Lake Houston.

I was so impressed with how we all worked together to make this possible and it was so cool to be a part of such a wonderful group of loving, caring and compassionate individuals. Together, we proved that people of all abilities can enjoy water sports together!

A huge Thank You to Ted Galanos and JoAnn Caliva for inviting Jeremy Bostic and I to come to experience this. Another huge Thanks to all my new friends who inspired and taught me so much during my first day: Rodger Randall - Founder of TAA, Lindi Mouton, Roni Thelen, Red Ross, Diana Carroll, Steve Rodgers, and Tim Thelen. I appreciate all that you’ll do to help everyone have a safe and fun time together! For volunteer info or to learn more about TAA visit: www.taasports.org or call (832) 435-6253.

**Image Descriptions:** 1) In this photo from left to right, a volunteer, JoAnn, Ted and I are sitting inside a big 4 person float tethered to the white boat behind us and we’ve got big smiles on our faces while waving goodbye before we go off for our wet ride over Lake Houston. To my left, smiling and waving too is Lindi Mouton, who is a PTA (Physical Therapist Assistant) who is one of several other volunteers that helped us get into our float safely. 2) (clockwise from left to right) Chelsea is posing next to colorful adaptive sitting ski-boards with colored insulation pipe foam.
Images continued: around them to also help them stay afloat and create a cushion for the disabled sit-skier. 2) A little boy in a wheelchair is being helped into the water on a ramp by three TAA volunteers. 3) Chelea’s friend Ted Gellanos invited her to this year’s event. In this photo he is Sit Skiing with a side skier. 4) Chelsea and Jeremy with the group of TAA volunteers standing and sitting outside in the grass with several people sitting on two pickup truck beds.
30 Study Participants Requested

My name is Kimberly Aguillard. I am a blind researcher completing my Ph.D. in Health Care Management and Policy. My life experiences and interactions in various intersectionalities have shaped my research interest. My dissertation is exploring gender-based violence among women with disabilities who lived in rural (outside of major metropolitan areas) communities while experiencing violence.

Several factors contributed to my interest in this issue and population. During the #MeToo Movement I witnessed many of my colleagues and friends in the disability community courageously come forward to discuss experiences of violence. Around the same time, I was flooded in Hurricane Harvey. I had family and friends available to help me, and I live in Houston where there were some resources available to assist people with disabilities.

The town where I grew up also flooded. It is a more rural area, and I learned that many people with disabilities had struggles evacuating, and rebuilding/recovering due to access and communication barriers. With natural disasters, we as a society have months or years to plan, yet there were not adequate services to assist people with disabilities.

I wondered about the ongoing crisis, related to violence, especially in rural areas. I wanted to learn what women with disabilities do in this circumstance to learn about what help is available, access that help and support, and build personal resilience to keep going through that experience. I know that people with disabilities are experts on living with a disability and that they are the key to shaping policies and programs.

I am interviewing women with disabilities about their experiences of violence in rural communities (defined broadly as locations outside of major urban centers). I will compensate participants with a gift card for their time and expertise.

The study findings will be used to improve and strengthen programs and policies to serve women with disabilities who have experienced violence. If you or anyone you know is interested in learning more, or sharing your story to contribute to the understanding of women with disabilities’ experience of violence in rural areas, please contact me by calling or texting (713) 487-7640 or emailing Kimberly.a.aguillard@uth.tmc.edu.

Please write RSRS for Rural Safety and Resilience Study, in the subject line. These narratives will inform policies and services, filling an existing gap in research and awareness.

Please pass this study announcement on to your networks. Thank you in advance for working with me to highlight and better understand the intersectionality of disability, violence, and rurality.
As the Founder of CN Vision Image Consulting, Chelsea Nguyen and her team were thrilled to be exhibitors during the College and Career Expo at Envision’s 2019 Level Up Conference. You’ll learn more about this amazing conference in this month’s article “Empowering Young People to Soar With Passion & Purpose.” However, the focus of this summary is to highlight a video demonstration of the CHI Lava Ceramic Pro Spin N Curl.

Envision’s Hannah Christenson, one of the lead coordinators of the Annual Level Up Conference, takes us on a guided tour of the Expo via Facebook Live. In the video, you get to meet some of the exhibitors and students who participated in the Level Up Conference. At at 10:17, you’ll even get to meet John Ficca, Founder of Hands-On Education who has now joined forces with CN Vision Image Consulting to provide quality training. On the video at 16:24 you also get to hear from Envision’s President and CEO, Michael Monteferrante, who gave the event an A++ rating.

The CN Vision Image Consulting and team are featured in the video at 12:09 where we discuss the importance of putting our best selves forward. My company helps people learn the non-visual as well as adaptive skills they need to be self-confident, independent and empowered to achieve their career and life goals. Part of this process involves caring for ourselves so that we can present a polished appearance.

In the video, Alison Roets, who was attending the Expo was spontaneously filmed by Envision using this amazing tool and this is what she had to say when asked why she likes the CHI LAVA Spin and Curl...

I really love the Spin N Curl so much because it allows me to look professional and put together without someone having to help me do my hair. I really like how easy it is to use and have already recommended this styling tool to several of my visually impaired friends. I was born with rod cone dystrophy and have peripheral vision. Which means I can see out of the corners of my eyes, but have no central vision. As a visually impaired woman myself who loves to wear my hair curled at times, it really makes it easy for us to do our hair without having to see it and we can do it all by touch without getting burned.

The CHI Lava Ceramic Pro Spin N Curl, also what I call “the Beeping Curling Iron”, is an excellent styling tool because of its safety and ease of use. Check out the expo video at www.facebook.com/HelpEnvision/videos/356465988385212/

To purchase one for yourself please visit this link to the CHI website: https://chi.com/product/chi-lava-spin-n-curl/

Image Description: Photo of Chelsea and Alison Roets. Chelsea is showing Alison how to use The CHI Lava Spin and Curl that Chelsea also calls it “the Beeping Curling Iron” on a mannequin head. Alison’s leans over to hear the Spin N Curl “beep” to let her know that it is done curling the hair and it’s now safe to pull it out and reveal the beautiful bouncy curls.
EMPOWERING YOUNG PEOPLE TO SOAR WITH PASSION & PURPOSE

BY STEPHANAE MCCOY

The version below is edited and was originally published on www.boldblindbeauty.com July 1, 2019

Meeting In Person
In late June I assisted CAPTIVATING! Co-founder Chelsea Nguyen to train youth at the incredible Envision 2019 Level Up Conference. As representatives of Chelsea’s company, CN Vision Image Consulting, our team’s purpose (Jeremy Bostic, Maxwell Ivey and me) was to connect, empower, and train blind and visually impaired high school students. The students from across the U.S. would learn non-visual grooming & hygiene techniques, professional and soft skills to help them become more successful throughout their lives and careers.

While I’ve known Chelsea only virtually for almost a year, the conference would be an opportunity for us to meet face to face for the very first time. Our shared values and a mutual desire to create a more inclusive and compassionate world are the driving forces in our friendship. From our first meeting at the airport where she hugged me she did the same with Every. Single. Person. We. Met.

A hairstylist by trade, Chelsea is an excellent image consultant, educator, speaker, and motivator. She has a way with people that makes them feel like they can accomplish anything they desire. What touches me about her is just how easily Chelsea is able to express how deeply she cares about others.
Chelsea does not have a disability. What she does have is an honest, heartfelt ability to empathize with those who do. It was an honor to accompany her, listen to her speak, and empower the awesome students at the event.

Envision 2019 Level Up Conference
From the moment we arrived at the Wichita State University (WSU) campus we knew we were in good hands. Baylee Almos, a Delta Gamma sorority member was our campus guide and an excellent resource for all our needs.

Envision 2019 Level Up Conference is a week-long training for blind or visually impaired students from across the U.S. Hosted at WSU, students receive valuable skills they need to successfully transition from high school to college and/or career.

From morning to night the well-organized event provided plenty of student activities. Keynote speaker Jessica Loomer opened the conference Sunday afternoon with a very inspirational and motivational speech about perspective. In her speech, she shared her personal journey of losing her sight to LHON - Leber's hereditary optic neuropathy (LHON) is an inherited form of vision loss. Although this condition usually begins in a person's teens or twenties, rare cases may appear...
in early childhood or later in adulthood. What was really helpful for the students and adults in the audience were some of the real-life on the job examples she provided. “It’s Just Coffee” mentioned throughout Jessica’s speech became a mantra for many of us who listened to her.

Sunday evening offered everyone the opportunity to let their hair down at the Level Up Live Kick-Off. Described as a social oasis and multimedia venue WAVE located in downtown Wichita is an eclectic indoor/outdoor hotspot. The entertainment space is huge and creatively incorporates recycled materials. There was plenty of singing, dancing, eating, laughing, and mingling with Envision staff, volunteers, and students. What a fun way to kick-off such a memorable week.

Modeling Positive & Passionate Leadership Behavior
Envision Leaders, Bonnie Cochran, and Hannah Christenson was extremely instrumental in keeping the program on track throughout the week. These two women who never missed a beat had inexhaustible energy to keep pace with their young charges.

There was very little downtime within the well-structured agenda. Every day after breakfast everyone attended the general session. Three sessions throughout the day (morning, afternoon, and evening) followed the general session with meals in between. After dinner, the students went to their evening sessions.

As representatives for CN Vision Image Consulting, our team’s presentation took place on Tuesday morning with an extended version in the evening. During the evening training, there was a co-ed hands-on demo then we broke out into boy/girl groups. In the groups, the boys learned how to tie a tie and the girls learned how to apply makeup.

The student’s readiness for the College and Career Expo was evident as they demonstrated the new skills they recently acquired. It was at the expo where they performed their elevator pitches, networked and toured the Envision facility. The evening prior they enjoyed networking and a four-course meal.

I can’t tell you how good it felt watching these young people increase their confidence by learning these new skills. All of the staff, volunteers, and guests modeled a positive can-do attitude which showed the students limitless possibilities.
The Envision 2019 Level Up Conference was a life-changing event for everyone who participated. This company really walks the talk to improve the lives of blind and visually impaired people.

The Lasting Impression
Everyone who participated in the conference was there to instill the skills these brilliant young people will need to succeed. Witnessing the transformation of these remarkable young people was extremely poignant. As they voluntarily stood to give personal testimonials about how our team impacted them proved the value of the training. Thanks go out to Envision and WSU for their warm hospitality. Also, thank you, students, for working with us and for your feedback.

Image Descriptions:
- Cover - Close-up of CN Vision Image Consulting team standing outside Envision Building. (Left to right Chelsea Nguyen, Stephanae McCoy, Jeremy Bostic, and Maxwell Ivey.
- Header - Steph and Chelsea with Level Up Lead Coordinators: Hannah Christenson and Bonnie Cochran (center) at the taco bar sporting our glow in the dark accessories.
- John Ficca, Hands On Education, and Chelsea are standing in front of a projection screen doing a hospitality presentation.
- Group Photo with Envision Management team and CN Vision Image Consulting team at Dinner Presentation. We are standing in front of a sign that says “Connect, Engage, Act.”
- CN Vision team (Jeremy, Max, Steph, and Chelsea) are at the front of the classroom full of students for our Tuesday morning presentation.
- Jeremy and another mentor are shaking hands with students during the handshake exercise. Steph and Max are practicing in the background with each other.
- CN Vision team is posing with Keynote Speaker, Jessica Loomer (3rd from the left) and 2 Starbucks representatives. Chelsea and the Starbucks team members are proudly holding out their Starbucks cups.
- Chelsea and Alison Roets at the Envision College and Career Expo. Alison is holding the CHI LAVA Spin and Curl heated curling iron and Chelsea is holding the CHI Hairspray.
- Group photo of Envision Mentors and CN Vision team in front of WAVE for Level Up Live! All of us are wearing fun glow in the dark accessories.
- CN Vision team selfie holding Level Up cookies. (L to R) Jeremy, Chelsea, Steph, and Max is in front of us.
- Chelsea and Steph are standing holding their Level Up cookies for the camera.
HOW I GOT MY RUNNING MOJO BACK AFTER SIGHT LOSS

BY JESSICA LOOMER

Seven years ago I was diagnosed with Leber’s Hereditary Optic Neuropathy after losing central vision within six months. Losing vision is extremely difficult. I had so many good days, but so many bad days too. I knew it was important for me to continue to do what I love - to stay active!

I used to run when I had vision, but I was just running for the cute clothes, you know? After losing vision, I was introduced to the Achilles International running group. This was a game-changer! I learned about running with a guide and the opportunities for me exploded. I started meeting new guides and created this amazing network of guides. My guides are amazing - they are kind and patient. They run next to me with a tether (a shoelace with a loop on each end) and we run side by side. They describe everything around me from cactus to trees to changes in pavement and railroad tracks. They count down for me when we are approaching a curb. They never miss a beat and allow me to run free!! It’s absolutely amazing, I am able to run with my new friends just like anyone else.

Running has given me many things, but the greatest gift has been the people it has brought into my life. ~Unknown

Throughout my running journey, I have moved twice! Each time I need to find a brand new group of guides. There are some amazing resources out there to find guides but the one I always go to first is United in Stride. United in Stride is an awesome resource where blind/visually impaired runners can type in their zip code and find sighted guides! Likewise, sighted guides can go and register making themselves available to guide. I count on this United in Stride to help me find guides to train for the events that make a positive impact in my life - California International Marathon, Boston Marathon, New York City Marathon - and the list continues!
I am extremely grateful for my guides, who I now call my friends. They are my eyes and give me the opportunity to do what I love! I am the happiest runner you will see on the path. Most days I am chatting away about some fun adventure I have planned. My next adventure? I am running Hood to Coast with the very first blind/visually impaired team. All 10 B/VI runners have 10 amazing guides that are traveling from all over the country to run this 200+ mile relay. This is an experience of a lifetime and I am so excited.

The journey is hard sometimes, take advantage of the resources out there and make new friends along the way! I found my passion in running - What’s yours?

If you would like to learn more about United in Stride, please visit: UnitedinStride.com

If you would like to help support our team to raise money for this fantastic organization, please donate at: https://www.crowdrise.com/o/en/campaign/united-in-stride-runs-hood-to-coast/jessicaloomer?utm_campaign=oc&utm_medium=facebook&utm_source=crowdrise&fbclid=IwAR1XCmiE01IBOccQwBAZQonOgRcywxhQQibR4PWWVIdjo_1mfUX9zE3qeNk

Photo Descriptions:
• My first 5k I ran with two of my first guides! I am wearing an Achilles International jersey and hat.
• One of my guides is taking a selfie of us running the Phoenix Half marathon. We are all wearing matching bright blue shirts!
• A side profile shot of me and my guide at the approaching the finish line at the California International Marathon. We are perfectly synched and have matching strides.
• This is a picture of me and my four guides dressed in Achilles International gear at the finish line of the New York City Marathon! We have the biggest smiles on our faces!
If Only Everything In Life Was Black And White

BY VICTORIA CLAIRE

This month I would like to share with you the pre-sculpture creative process. As a public speaker with the advocacy work I am involved in there are often Q&A sessions at the end of my talks, I get asked the following on most occasions:

“How am I able to sketch my designs or do I just create the visual in my mind?”

This has been an ongoing process for me over the last 25 years of my profession. As I have a background in studying graphic design, I have always had the work process of designing and evolving my designs on paper, initially, I would just draw the ideas, allow them to evolve until I was happy with the end result. However as my sight has deteriorated over the years I have had to keep adapting how I do this. One of those adaptions was to draw large, my sketchbooks are A3 size books, I would design as large as I could, using one page per idea, this then had to be adapted again, I was having real difficulty seeing the lines I was drawing in pencil, so I began to use charcoal to sketch with. This has worked well for some time, but then I was beginning to notice that I was having to push harder with the charcoal and create thicker, darker lines, this then began to look very messy and undefined.

I had a period of creating work by using my ideas that were in my mind, that works ok as long as what I was creating wasn’t for a client, for example, I was able to use this technique when creating some of the collection for the exhibition Blind A Sixth Sense. When you are working on a collection for exhibiting it can be much more free form as there are no specifics to consider, only what I want to portray, however considering I create a lot of my work to commission, this would not work in the same way. My clients usually come to me with an idea of what they want, I then would go away and create several different designs and then present them to my client so that they could choose what portrays what they would like best.
Of course, if I could project my thoughts and the visuals in my mind to my clients this would be perfect! However, we do not live with that kind of technology yet!

This made me re-evaluate how I could continue to present preliminary sketches to my clients. I have had to be open to adaptivity through my sight loss journey, in fact, it is one of my advocacy messages. This is what inspired the solution to the designing problem that I was facing. When using devices such as my iPhone, iPad and Mac book, I use inverted colours, for me a black background with white writing works very well, this made me think about using the same technique when sketching. I bought an A3 sized sketchbook that had black paper pages, I then bought white pens and chalks to draw with. Initially it felt very strange to draw in reverse colours, it went against everything I had been trained to do at art college. For example, when I draw it is in a very 3 dimensional way, this is due to being a sculptor, I show the 3 dimensions by using a lot of shading and highlighting, how does one show shadow on a black page? I had to almost re-train myself with my drawing skills and learn to think of everything being inverted so that the shade becomes the light and the light becomes the shade! After practising this with all the past 5 commissions I've had recently, I feel I have finally mastered this to a point where I am happy to share the designs with my clients.

I think for me I was a little stuck in my ways of how I have always done things regarding sketching, I had to allow myself to be accepting to the fact that like my designs evolve, so do the ways of how my creativity is presented.

So I hope by sharing this with you it gives you an insight into how a visually impaired artist works and may inspire you to look for different solutions to any practical difficulties you may come up against. It's about allowing yourself to embrace alternative, adaptive ways of doing things, like me, you may surprise yourself with how well the new way of doing things works out and feels, it is very rewarding to continue doing the things you love in life, to be able to have the open mind that will allow you to break down any limiting beliefs and just keep growing through your adversity.

For further information about Victoria Claire please visit: www.victoraclairesculpture.com or for her advocacy work visit: www.victoriaclaire-beyondvision.com

Descriptions: The first 3 images are sketches drawn with white chalk on black paper. The second three images are the finished sculptures: Beautiful Hesitance (bird preparing to take off), Mind's Eye (and eye with a chakra suspended as the pupil), and Together (two rings forged together).
Cole Sprouse, who appears as a heartthrob on TV’s “Riverdale,” uses art as a method of therapy and expression to deal with such a devastating situation. The third character is Poe (Moises Arias), another veteran of hospital life and best gay friend to Stella. Twenty-five-year-old Arias plays a convincing 17. He is the most experienced of the three young actors and often outacts his castmates. He is the one person in the film who actually appears as if he is truly frail and seriously ill.

The film does a good job of portraying long-term hospital life for teens, especially how they explore the hospital and break up the routine by sitting in public areas when the daytime crowds are absent. This film hints at the grueling and repetitive life of a chronically ill patient. There is one scene where Stella is wearing an AffloVest, which helps to vibrate the torso so that the
excessive mucus that forms in the lungs of a person with CF is able to be loosened and then expelled. We get to see Stella spitting out the mucus into a cup. This brings a touch of realism to a film that makes a long-term hospital stay seem much more pleasant than it actually is. The AffloVest itself costs $6,500. Poe talks briefly about the financial burden of having a chronic illness. He is about to turn 18 and then he will no longer be eligible for full healthcare coverage under his parents’ plan. Then what? Does he have to rely on a partner to take care of him into his adulthood? These are the very real questions that face a person living with a disability.

This film wants to give a hint of the struggles of chronic illness but a deep dive into these realities are not really romantic for a teen film about young love. Cystic fibrosis is used as a vehicle to keep Stella and Will apart when they start falling in love. The tragedy of the film is that as these two beautiful young people get emotionally closer, they are still kept apart by the rule of six feet apart from all CF patients.

One of the realities of living with a disability is that you experience a great deal of loss -- loss of mobility, autonomy, independence, and ultimately, loss of life itself.

Stella is on a waiting list for new lungs. The last scenes of the film feature the flurry of her prepping for and receiving a new set of lungs. “Five Feet Apart” is a good vehicle to raise awareness of the need for organ donation. Hopefully, the young people who view this film will be inspired to sign up for organ donation on their newly-minted driver’s licenses. As someone who has had two major surgeries in the recent past, the last scene of Stella waking up from her surgery haze was so unrealistic to me. Even though I understand the poetry of the scene, my recent history kept my brain from accepting the scene for what it was.

This film is a good jumping-off point to discuss living with a chronic disease or disability. The film is bound to be shown in youth groups and sleepovers for many years to come. I hope the love story doesn’t overshadow the opportunity for discussion about some very real and serious subjects that are also included in the film. “Five Feet Apart” is now available for streaming and on DVD and we are GIVING AWAY a Blue Ray edition of the film, including a digital download. I hope to include information on organ donation to the winner.

Image Description: A blurred photo of a hospital corridor with a person walking down the hallway.
Pamplona or Iruña is the capital of Navarra, Spain. Founded by the Romans, this city is famous worldwide for the San Fermín festival, with the bull run, that takes place annually from July 6 to 14. Pamplona has a monument dedicated to the bull run. This event brings people from all around the world to run in front of six bulls through ancient streets at 8:00 am.

The center of Pamplona is familiar due to I have seen it many times on TV every July. The City Hall square is where the festival starts with the “chupinazo” (the firing of a rocket).
The other main square is the Castle Square which is the social life center of the city. This square had a castle for 3 centuries but now there is no trace, even so, it is a beautiful place with colourful buildings, all built with a similar style.

Pamplona surprised me, I found it very beautiful with its ancient streets, its historical places, and its tasty food. This ancient city is surrounded by walls and it has a well-conserved citadel perfect for a walk.

We found the city quite accessible and nice. We also notice that one day is not enough for a proper visit so I am sure I will visit again.

**Image Descriptions:**
1) “The Monumento al Encierro (Bull Run Monument) is a full-scale bronze sculpture that depicts eleven spirited bulls charging through the streets, snorting on the heels of the runners (called mozos) as they sprint toward the Plaza de Toros with all their might. A few of the runners have stumbled and fallen to the ground, and this hyper-realistic monument depicts the anguish and fear etched on their faces.”
2) Plaza del Castillo (Castle Square) boasts an ensemble of striking architecture, tapas bars and a charming mix of locals, tourists, and street performers.
3) Standing tactile map complete with braille.
4) Beatriz is posing with a friend. Both are standing in front of City Hall a Baroque-style building.
5) Ancient cobblestone street where all the buildings have balconies.
6) A photo of Beatriz posing for the camera in front of a building.
One of the things I really like about working within the virtual disabled community is our shared passion for creating positive change in the world. For example, my YouTuber friend, Sam Seavey of The Blind Life, asked me a while back if I’d help promote a new project he’s been working on for a few months. During our conference call, without hesitation, I agreed to help him.

Technology is evolving so rapidly and it’s really exciting for those of us living with disabilities to be able to participate on various levels from design to implementation to promotion. Being heard is a critical piece to advocacy that is sometimes overlooked by companies. So when we find a company who is looking out for the best interest of those within the disability community it grabs our attention. Enter BlindShell a cell phone designed specifically for the visually impaired.

The BlindShell Classic cell phone was designed to be simple and easy to use. Everything on the phone is audible so every time a button is pushed the phone lets the consumer know what they are doing or where they are on the phone. There are a lot of great features on the BlindShell, my personal favorite is the built-in “object tagging” availability. With this feature you can scan premade QR code stickers included with the phone for labeling purposes. You simply scan and record a custom voice label assigned to a specific QR code. This is helpful in identifying all sorts of household products like medicines, pantry items, CDs, DVDs, etc.

The camera function is also really cool as you can take a picture of an object, record what it is, save it and then retrieve the saved image with the recording.

To check out all of BlindShell's features and to learn more about the cell phone please visit: www.blindshell.com. While you're there you might want to check out Sam's video review on the phone.

**Image Descriptions:** Header is the BlindShell orange logo that slightly resembles an eye. The second image is the black and red versions of the BlindShell Classic phone with tactile buttons.
“Bringing more understanding, compassion, and inclusion to our communities by connecting and enlightening people of all abilities.” ~CAPTIVATING! Mission Statement

The past two months have been very exciting for CAPTIVATING! and we are eagerly looking forward to what comes next. Among other things our team is expanding so that we can offer our readers more valuable content around topics like self-employment for example. At the same time we are looking for skilled volunteers in the areas of graphic design, social media management, and marketing. If you or someone you may know might be interested in learning more about how you can become a CAPTIVATING! team member you can contact us by email at info@captivatingmagazine.com or on any of our social media platforms (our Twitter handle is @WeRCaptivating, Facebook and Instagram are @CaptivatingMagazine).

In this special edition of CAPTIVATING! we've featured some amazing organizations who are doing so much for the disability community. Organizations like Texas Rehabilitation Association, ALS Association Texas Chapter, Texas Adaptive Aquatics, and Envision help those who are living with disabilities live more fulfilling lives and we thank you!!

We have a special surprise coming up in our September edition so be on the lookout.

As always we hope you enjoy this issue of CAPTIVATING! Magazine. We invite you to submit questions, articles, and ideas to editor@captivatingmagazine.com or through our website at www.captivatingmagazine.com.

Thank you!!

CAPTIVATING! "The power and possibilities of inclusion are limitless"