Brushing beauty

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Inspirational language and disability

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Hundreds descend on Norfolk

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Obi Robot helps many feed themselves

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Gone fishing

This past June I took a fishing trip up to Northern Wisconsin with my buddy Mike; we spent several days fishing for smallmouth bass. I spent most of the time casting spinner and jerk baits. I ended up pulling in some nice fish, but Mike ended up kicking my butt yet again, catching the nicest fish of the trip. Honestly, while I enjoy catching fish, I enjoy the experience even more. It reminds me of my dad.

When I was in ninth grade, my dad took me on a short trip up to Eagle Lake in Ontario. He said he wanted to see how I handled myself in the boat before he took me on the big trip with the rest of the guys. I remember sitting out in the rain one early October morning hooking and reeling in 2-4 pound Walleye, getting them up to the boat myself. It was a feeling of independence I had not often felt before. Suddenly I did not see myself as son in need of a lot of help; I saw myself as his equal, one of his fishing buddies.

Of course, I still relied on his help, but as I went on more trips, I started gaining more and more skill. At one point I started trying to cast out my lures. At first, dad was a bit dubious, not wanting me to accidentally hook myself or especially to hook him with an errant cast, but this made me want to do it even more.

Going on fishing trips is a good reminder to me of who I am, especially as an AMCer who values independence, but it also reminds me of my need for others because there are things I still cannot do. The experience has taught me how to strike a necessary balance.

Fishing was one of my dad’s greatest passions, and even though he has been gone for three years, a part of him still lives on every time I feel a big tug on my line.
AMCSI update

AMCSI President
Chris Hartwick
thanks volunteers

We had an amazing time in Virginia for the 14th Annual AMCSI Conference. The Hilton Norfolk The Main was a great place to stay. Michele, and crew, did an awesome job working behind the scenes to put on an awesome conference. It was one of the most attended conferences to date.

For those who may not know who the Board of Directors are, here is a rundown: Ani Samargian - Founder; Chris Hartwick - President; Joey Balistreri - Vice President; Alexis Record - Secretary; Don Bahr - Parliamentarian; Jared Kampf - Treasurer; Ileana Hernandez, Melissa Snyder and Jennifer Paradeis - Members at large; Harold van Bosse - Medical Director.

If you would like to contact us for any volunteer work, needs, concerns, or questions about the organization, please feel free by calling 1-805-55-AMCSI, or emailing us at BOD@amcsupport.org.

Sincerely,
Chris

Grants available

AMCSI is continuing to offer several grants to AMCers and/or their families.

The AMC Research Fund awards $5000 grants to researchers looking to advance their studies relating to AMC. For those attending college in the fall semester, AMCSI is making its Scholarship Fund available to anyone affected with AMC. If you missed this year’s deadline, get your application in early for 2020. The organization is also offering AMC adoption grants, ranging from $500 to $2500. The grants are awarded to home-ready families adopting a child with AMC.

All grant applications can be found on the AMCSI website, www.amcsupport.org. For questions regarding the application process, email the Board of Directors at amcsibod@gmail.com.

Membership increases

AMCSI has increased its membership roll to 344, up 75 from last year. Memberships include single memberships and family memberships. Membership runs from January to December. Benefits include early-bird access to registration for the annual conference to be held next year in Scottsdale, Arizona.

For more information on membership pricing, go to the AMCSI website at amcsupport.org.

T-shirt contest

Attention artists. Are you interested in submitting a design for the 2020 AMC Awareness Day tee shirt? The contest opens up October 1st. Start planning your designs now!
Riding in an elevator to the second floor of an old, musty building in Philadelphia, Jessica Ruiz was fighting off her nerves as she rode to her first job as a makeup artist for a local fashion show in the fall of 2015.

When she emerged in her wheelchair and rode to the corner table to set up her makeup station, she felt overwhelmed by the controlled chaos of the scene. She watched as the 75 models in the show began to sit down to have their makeup applied, model after model at other stations around her.

For about 4 1/2 hours she waited.

No one came.
Jessica, an AMCeR who taught herself how to apply make-up by holding a brush in her mouth, spent the time fighting off “heart-wrenching” thoughts that she wasn’t good enough, that she did not belong.

Finally, at the very end of the show’s first day, the director sat a model in her chair because none of the other artists were available.

“She was honestly reluctant to even sit in my chair. She felt like she was getting the cheaper end. The director told her she had no choice.

Jessica nervously placed the brush in her mouth and began to apply a basic, natural-look foundation. She then worked on the model’s eyelashes and lips, using slow, precise sweeping motions.

When the model saw herself in the mirror, her disposition changed. The result was “phenomenal.”

“She was completely blown away,” leaving the station to speak with some of the other women, praising Jessica’s work.

When she arrived for the second day of the show, three models were already lined up to get their makeup done before she could even get her kit unpacked.

By the end of that day, she did makeup for 33 women, and since then, her life has not been the same.

Jessica, 30, who owns and operates Dreamy Eyes Artistry, acknowledges that the road to her success was paved with difficulty and prejudice.

She graduated from Widener Memorial School in 2008, a school for persons with physical disabilities in Philadelphia. As a self-described “tom-boy” throughout middle school and her early high school years, she said she did not mix well with many of the girls in the school. She was often bullied.
“I hated the cattiness,” she said in an interview with AMC Today. “When you are being bullied, you literally lose a sense of who you are. Your head is so filled with all of your hurt, thoughts that people put in your head. If you are constantly hearing it, you start seeing it.”

Jessica decided to break out of this emotional rut and redefine herself. She started to do makeup because she needed to do something to throw those girls “for a loop.” She started applying her own mascara and eyeliner, and she discovered she was good at it.

“Even if it’s just a little bit of mascara, you can make yourself feel good,” she said. She also discovered how happy she could make others, when a friend asked her to apply her prom makeup in 2007.

“I was literally petrified to touch this young girl’s face.” She heard “horror stories” about botched makeup jobs. She wasn’t even sure how to match a foundation to the color of her skin. Later on, she received a letter from her friend’s mom expressing her joy about Jessica’s beautiful work.

The beauty industry was not so welcoming: three different cosmetology schools rejected her.

When she arrived for her interview at a beauty school in Philadelphia, they assumed she was a customer. The manager came out and seemed surprised she was even applying. Even after Jessica showed them some of her work, they were “standoffish,” telling her it was not the best facility for her because of her arms and limited mobility. She offered to pay them cash out of pocket because she knew she would not qualify for financial aid.

“They very bluntly told me that I would never make it in the industry,” calling her technique “unsanitary.”

“They shredded my application right in front of me.” They told her that it was part of their application process, but she said she had never heard of that being done before.

Another school said she needed to bring in her own models because their models would not be comfortable with her being so close to their faces.

She stopped applying, calling the experience a “punch to the gut,” sending her into a depression. “I was very ashamed of even having my disability, and I hate saying that. ...It took me to a very dark place.”

It took a while, but she began to accept her limitations and realize she needed to adapt to them, finding her own way. She began to believe that her arthrogryposis could be a source of strength.

“It really took everything in me to push my pride away.”

Jessica decided to teach herself on “YouTube University” where she discovered all the instructional videos she needed for free. “I literally had to adapt and reinvent the way cosmetics were applied.”

She started posting some
before and after photos of her work on Instagram, but she still felt too ashamed to show pictures of herself applying makeup, saying she was “so afraid of being denied yet again.”

After being encouraged to keep trying, she finally said “screw it” and posted a single picture of herself, holding a makeup brush in her mouth. As her skills increased she started posting more and more pictures of her own makeup on Myspace, then Facebook, then Instagram, where she said her work began attracting attention.

Eventually, she started reaching out to cosmetic companies and local fashion shows where she was finally hired. A year after her first fashion show, she was named lead makeup artist for the next season. The show coordinator publicized the hell out of her, and got her on live TV and into magazines. She said that’s when her business really started to take off, expanding into Atlantic City and New York.

Jessica lives with her husband Robert Rodriguez who has a form of dwarfism. “Robert helps me with a lot of things I need like helping me shower and getting dressed, and we are coming up on our 15-year anniversary despite the stress of us both having physical limitations.”

Jessica and Robert met in school. He explained that, as disabled people, the school did not adequately prepare them for the work world, focusing mostly on “life skills.” This lack of preparation contributed to the struggles she faced in the beauty industry, but she refused to settle for just any job offered to her, as many do.

He takes pride in the barriers she has broken and in the way he has paved the way for others. “She just makes me feel proud because she is doing what she wants to do,” he said.

Robert enjoys spending time with Jessica, assisting her with special effects makeup, especially around Halloween, making people up as zombies.

He also likes meeting the many “cool” and interesting people in her life. “She works with everyone. She’s not biased, being disabled or not. Everybody’s the same to her.”

Jessica works out of a studio in her home in Philadelphia. She does travel out to customers for an

“She works with everyone. She’s not biased, being disabled or not. Everybody’s the same to her.”

Jessica poses with her husband Robert who she met in high school.

Photo courtesy of Jessica Ruiz
extra fee. After they book online, she typically sees five to six customers a week, but business picks up during wedding and prom seasons when she is frequently double booked.

... 

Jessica was born on January 4, 1989 at Abington Memorial Hospital in Philadelphia. Her legs and arms were pinned behind her. Additionally she was born with her intestines outside of her body, which required immediate surgery.

Jessica was raised by her grandparents who supported and pushed her. Around ten or 11 years old she remembers taking a trip to Wildwood, New Jersey, a favorite family destination. Once there, Jessica resolved to walk the entire distance of the city's boardwalk. Her grandparents spent the weekend in the sunshine and salty air walking with her.

Often holding her grandfather's hand, she would walk until she needed to rest. “When I got really tired they would just sit down next to me until I was ready to get back up and start walking.”

When they finished, she realized she could do anything. “It was a beautiful day to break a barrier for myself.”

Now as an adult she feels compelled to inspire young kids with disabilities. “I want to show these kids it's possible to do whatever you want. ...That's where my heart lies.”

Over the years she has met a number of children with AMC. She said she enjoys listening to their hopes and dreams. She wants youth to see the “silver lining” in their disabilities, not seeing past them but to see the beauty within them.

On one occasion she even left a family member's funeral to meet Brayden, an AMCe who was scheduled to have surgery. Jessica said her grandmother, Dawn, messaged her, requesting a meeting. She met Brayden and one of her friends, who also has AMC, for lunch at Penn's Landing in Philadelphia. They ate chicken fingers, and the girls were amazed at how she was eating, and drinking.

“[Brayden ] actually reminds me of myself a lot, so when I see her, it's kind of like I’m looking in a mirror at myself at a young age. ...She embraces her disability so phenomenally: it's beautiful.”
In her widely viewed TED talk from 2012, Australian disability activist Stella Young coined the term, “inspiration porn” to specifically describe the portrayal of disabled people as sources of inspiration, especially in the mass media.

“...We’re objectifying disabled people for the benefit of non-disabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, ‘Well, however bad my life is, it could be worse: I could be that person,’” she said during the presentation entitled, “I’m Not Your Inspiration, Thank You Very Much.” Essentially, Young, who died in 2014, objected to inspirational language because she believed it is predicated upon the idea that being disabled is inherently a bad thing, something to overcome, thus reinforcing a negative stereotype.

The arguments surrounding inspirational language did not originate with Young, but she certainly energized the conversation which has become a source of controversy. Many people inside the AMC community believe in the negative influence of inspiration porn, and they have extended the argument beyond mass media portrayals, to the way disabled people are described on social media and spoken to, or about, in general conversation.

However, there are many others who believe in the positive value of inspirational language. To varying degrees, many AMCurmers embrace it, describing themselves as inspirations. Additionally, many parents openly celebrate their children as they learn to work around their AMC.

Needless to say, the conversation around this issue can inspire heated debate. The following article presents the viewpoints of four different people in the AMC community. The purpose of the piece is to educate our readers about the controversy and hopefully promote some understanding among those who disagree. Bear in mind, the controversy around inspirational language is not a simple, two-sided issue, and it’s impossible to represent all the nuanced opinion surrounding it.
Doug Moreau, a 57-year-old AMCer from New Orleans, thinks inspirational language should, for the most part, be viewed positively. “If it’s kindness, there’s no reason to be angry about it,” he said.

Moreau, an English teacher and sports announcer, has faced difficulties, including job discrimination, yet he disagrees that inspirational language distorts the image of the disabled experience.

“Are we inspiring? Yes we are,” he said in an interview with AMC Today.

Nevertheless, he understands why some are offended, and he said he was apt to feel the same way at an earlier age. As a young man, he often felt the sting of rejection, but he also admits he felt insecure about his disability which lead to anger.

“It felt uncomfortable because I was uncomfortable with myself. ...It’s easier to blame others than to dig into yourself and discover your positive qualities. ...Now I’m so much at ease,” he explained.

Moreau is not bothered by able-bodied people who use inspirational language since he claims they have a legitimate fear of becoming disabled themselves and positive examples help ease this fear. “We provide hope in the event that someone who is able bodied losses ability. Who am I to deny someone their sense of hope? That’s a huge compliment.”
Recently, rehabbing from hip replacement surgery, his therapists praised him for his work ethic and for setting a good example. He said it pleased him to be seen as a motivational force.

While he acknowledged able-bodied people can, at times, be patronizing, he argued it is important to feel the tone of the speaker when assessing intent, but it is also important to become aware of one’s own feelings, especially anger.

Unlike people uncomfortable with inspirational language, he believes it’s mostly appropriate for disabled people to celebrate tasks of daily living. He said he was once told he would never walk. “[Walking] is an accomplishment, and it’s something I don’t take for granted.”

He said the parents of disabled children generally live on an emotional roller coaster, wanting their kids to achieve independence, and he does not fault them for using inspirational language.

He believes, however, that some parents go too far. He called overpraising disabled children, multiple times, for accomplishing the same task, “foolishness,” inhibiting them from progressing toward new milestones of independence. He added, this problem extends beyond the disabled community.

Alexis Record

Alexis Record, who has two children with AMC, initially used inspirational language to refer to her children; however, as her daughter Laelia grew older, she began expressing discomfort with being described as “an inspiration.”

“…You have one mosquito bite: it’s no big deal. Saying someone’s an inspiration: it’s no big deal. Hearing it over and over, over the years, is like having a thousand mosquito bites, and the itch can’t be ignored, and it becomes a detriment to your livelihood, to how you are viewed, to how you make friends.”

Record now believes inspirational language can be detrimental, especially in certain contexts. She describes inspirational language as “a micro aggression.”

In an interview with AMC Today she said, it’s “something very small, like a mosquito bite that can cause harm over time. You have one mosquito bite: it’s no big deal. Saying someone’s an inspiration, it’s no big deal. Hearing it over and over, over the years, is like having a thousand mosquito bites, and the context in which the word is used matters. She explained if another disabled person sees one of her children accomplishing a daily living skill, and it inspires that person to try that skill, she said using the term “inspiration” is appropriate. However, she said when able-bodied people are inspired because they see her children’s lives as “so much worse, situationally,” this becomes a problem. “No, you don’t get to do that. You don’t get to tell my kids that their situation is worse. You don’t understand them. You are not in their head space.”

When her children come in contact with someone who continually uses inspirational language to describe them, she said they employ a three-step approach. The first time they hear it, they say “thank you.” The second time they hear it from that person they try to deflect it. The third time, they educate.

Record said she would not tell someone they “are wrong” for feeling inspired, but she also feels a responsibility to protect her children.

Now she only uses the language when her children do something to inspire good in the world, like doing a beach cleanup or working with the homeless.

The word “inspiration” should not be used to describe someone for simply existing; its usage potentially “dehumanizing,” she argued.

She believes, however, that
Nicole Sidebottom is a licensed, professional counselor living in Colorado. As a person with AMC she agrees that using inspirational language to describe people with disabilities can be problematic, yet she also believes that the intention of the person using the language should be taken into consideration and that dialogue needs to occur.

She told AMC Today the able-bodied community can be out of touch with the disabled community because they just assume that the lives of disabled people are hard, sometimes deserving pity. She said she understands the intention of the term “inspiration porn” and agrees disabled people are often objectified.

“I think it’s our job to stand up for ourselves, to advocate for ourselves, and to talk to people about how their language impacts us. ...We have the ability to influence the direction of that conversation.”

She believes the impact of the language could occur on a spectrum: on one extreme, she said, it can go to the heads of disabled persons; on the other extreme, they can choose to be offended and become angry. Staying away from either extreme and initiating a kind, open-ended dialogue is the better option, she explained.

She emphasized the context of inspirational language can vary from one person to another since disability is such a diverse experience. She said intention matters.

For some people just getting out of bed in the morning should be considered a tremendous feat, and it should be celebrated. On the other hand, she said there are others who should be celebrated for much more than their physical abilities or disabilities.

“If you tell me that you just got out of bed for the first time by yourself, I’m going to celebrate in their hearts, people want to be kind.”

“You have to be vulnerable enough to tell people how their language affects us and believe that people don’t want to offend. I think we have to believe that in their hearts, people want to be kind.”

On a personal note, she said, “I am still a bit uncomfortable when someone views me as inspirational, but I do my best to inspire others with my gifts and talents, and I try to find inspiration from those around me.”

INTERESTED IN CHANNELING YOUR INNER JOURNALIST?

Consider being a staff writer for AMC Today, or write a letter to the editor.

Drop us a line at amctoday.amcsi@gmail.com.
The humidity and extremely warm weather didn’t stop the nearly six hundred and forty people from attending the 14th Annual AMCSI Conference in Norfolk, Virginia. The conference, which ran from July 3-6 at the Hilton – The Main, featured a digitally friendly atmosphere, designed with the feedback from the AMC community throughout the year.

One difference from past conferences was that there was no guest speaker at opening ceremonies but rather an informal greeting from the Board of Directors and the conference planning committee. The conversation was what “we would experience” over the three days in Norfolk. The attendees were treated with a video created by Jessica Lappin, showing all the AMC families who wore blue for AMC Awareness Day on June 30th.

On a personal note, having the opportunity to see this event blossom over the last 14 years, I have been struck by all the hard work that’s put in place for the AMC community to come together and share their stories, struggles, and achievements. To witness the improvement and development of so many AMCers was a memory I will take home.

I had the opportunity to meet up with my friend Jake Gates-Ehlers. I met Jake when he was only two years old, and now, he’ll be entering middle school in the Fall 2019. He let me know that he loves coming to the conference because he gets to see other kids with AMC. He added that the swimming pool is one of the best parts of the conference.

The conference was not only about attending sessions. The planning committee made sure everyone was having a great time, especially after each day of sessions.

AMCSI Conference dives ‘Under the Sea’ in Norfolk

by Valerie Pepe
was over. Like the 2018 conference, the Prom Planning Committee organized its second prom, called “Under the Sea Prom.” The guests were entertained by DJ Anthony Fernandes Casanueva, a fellow AMCers who kept everyone on the dance floor. It was here that I walked around the grand ballroom filled with music, confetti, corsages and blue candy.

When I sat down to talk to a young adult, Carly Moore, from Nebraska, she summed up what the conference means to all of us. Carly said, “We are one great family. We are able to talk about our insecurities and daily living concerns with other young adults that have the same struggles. We don’t have to feel different because we have the same challenges.”

I looked over at Carly’s mom, and the pride in her eyes was so clear after hearing what said, “This is what it’s all about.” Another mom, Tiffany, a new attendee stated, “I was happy for my husband because he was able to talk freely with other dads on how to raise a child with AMC. The conference [offered] so much for the entire family. I especially loved the idea of the sibling sessions that were very helpful for my eldest child.”

There we so many new faces exhibiting and conducting seminars: Jessica Collins from Shriner’s Hospital for Children in Canada; A conference favorite Dr. Harold van Bosse from Shriner’s Hospital in Philadelphia, and many others.

Of course, Misha Walker,
AMCers and their families dance the night away at the second annual AMCSI prom. This year’s theme was “Under the Sea.”

Photos by Alicia McCavanaugh

The AMC International Ambassador was present. She spoke of her travels in 2019 and all the families she met in the United States and across the globe.

The conference location was in the heart of the largest naval town on the eastern seaboard. The families were able to walk to shops and restaurants only a short distance from the Hilton. Having the conference during the July 4th week brought something extra for the kids. The fireworks show on the riverfront was a spectacular sight.

When it came time for closing ceremonies, people reflected on the three days in Norfolk. As it happens every year, the families tried to guess where the conference would be held in 2020. We all took our seats for the last time together at the conference in the grand ballroom. We were treated to a picture show of the three days in Norfolk. Unlike other years, we didn’t have a speaker talk about his or her personal experiences at the conference, but rather the board and planning committee decided to have the board meeting for everyone to experience.

AMCSI Vice President Joey Balistreri explained that all the families should know the AMCSI budget and expenses, as well as where the fundraising efforts are used. The board let everyone know that at the 2020 conference there will be time set aside for the board to answer questions from any member.

Eventually the time came to learn where the 2020 AMCSI conference will be held. The conference planning committee asked all of the attendees to take an AMSCI quiz with their smartphones. The suspense of where the conference would be kept on building. Then finally on the screen, it was revealed that the 2020 conference would be held in Scottsdale, Arizona.
AMCSI partners with Obi Robot

If you have attended the annual conference, you might remember seeing a robot named Obi in the exhibition hall: it feeds people without the use of their arms. Recently AMCSI has entered into a partnership with Obi Robot to offer a special promotion for AMCers in need of the product.

Company spokesperson Rachel Dekar said, “The goal of the partnership is to increase awareness of both Obi Robot and AMCSI. In addition, we want to help make Obi Robot as accessible as we can for our AMCSI families while also supporting the AMC community with a donation to AMCSI.”

She explained AMCSI families who purchases an Obi Robot directly from the company will receive a discount, and a donation will made to AMCSI. “If Obi is purchased by a third party distributor or through insurance, there is no discount, but there is still a donation to AMCSI,” Dekar added.

According to the company’s website, “Obi Robot is providing an independent dining experience for people all over the world. ...Potential diners are welcome to try Obi and familiarize themselves with the features in the comfort of their own home or clinician’s office through the Obi Trial Program.” For additional information or to request a trial, go to the company’s web site: meetobi.com/amcsi.

As part of the partnership agreement, AMCSI has agreed to promote the Obi Robot via AMC Today and on social media. The company has already set up a web page to help promote AMCSI and its fundraising activities. The company has also agreed to share information on AMCSI via its newsletter and social media.

According to the company, founders Jon and Tom Dekar spent 10 years developing and refining the robot.

“Obi Robot is providing an independent dining experience for people all over the world.”

Meet Obi
The first dining robot of its kind.

AMCSI is pleased to partner with Obi Robot to offer a special discount program that provides empowering, independent dining experiences for individuals who cannot feed themselves.

Effective Food Capture
Obi's patented features allow for optimal and efficient food delivery.

Simplistic Operation
Obi can be operated with any part of the body that can activate an accessibility switch.

Dining Freedom
Battery operated and weighing only 7 pounds, Obi makes it easy to dine on the go!

To learn more about this special promotion, please visit: www.MeetObi.com/AMCSI