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Welcome to AMC Today, our rebooted, news magazine. As I have become more and more acquainted with people, like myself, who live with arthrogryposis, I have been struck by their tenacity and passion for life.

I belong to a vibrant community of artists, teachers, doctors, lawyers, accountants, and counselors. We are husbands and wives, mothers and fathers, and grandparents. We take risks, we inspire others, and we challenge ourselves.

I feel called to do this work, to write this story. It is our story. Yes, it is a story of struggle, but most importantly, of triumph. Last summer I heard of a woman who refused to bring her AMC child to the conference because she did not want to expose him to a group of people who “pity” themselves. I’m not sure how to respond to such a ridiculous stereotype, except to say it’s not true.

Over the coming months, AMC Today will introduce you to people who challenge the stereotypes placed upon us by our society and even ourselves, people who take their AMC and the difficulty that comes with it, turning it into strength. In this edition you will meet Scott and Summer Braddock who have defied everyone’s expectations, even their own. Their story exemplifies who we are as a people.

Also, I do this work in honor of my parents, who sacrificed so much for my benefit, who endured and believed. It is their story as well, the story of every parent who sees their AMC child and recognizes, not someone damaged, but someone beautiful and filled with potential.

AMC Today will keep you up to date on AMCSI, what’s happened and what will happen within the organization. The magazine will contain a quick-read news section and several features. Letters to the editor are always welcome.

Of this, I promise: the magazine won’t shy away from the difficulties many of us face, but it will never be a platform for self pity. It will focus on today, the life we are living, the life we have been given.

If you have story ideas, please send them my way. Also, if you have experience as a writer, and you would like to be a regular contributor to AMC Today, please drop me a line. Single article submissions will always be considered for publication.

I would love to hear from you. You may contact me at amctoday.amcsi@gmail.com.
AMCSI Update

T-shirt design winner named

We have a winner! Thank you to all who submitted artwork for the 2018 Awareness Day t-shirt contest. This year’s winner is Abigail Marie!

If you have an idea for awareness shirts for 2019, watch for the contest announcement in January of 2019. You can order your Awareness Day shirts for June 30th at www.eventbrite.com/e/2018-offical-amc-awareness-t-shirts

Congratulations, Abby.

(Disclaimer: the contest was done by blind vote with the president and founder not voting.)

Volunteers needed

AMCSI is looking for volunteers to staff several new committees to keep improving the quality of the services we provide to our membership. Volunteers are needed for a new fundraising committee, the Sunshine Committee, and a marketing team.

AMCSI President Lana Prater said that because the organization is growing so fast, professionals qualified to do specialized work are needed.

Due to its nonprofit status, AMCSI is required to follow a number of procedures when fundraising, and the new committee will help expedite this important work, providing more money for the membership. Volunteers on this committee will help to organize fundraisers and work with the online store on Facebook.

Volunteers on the new Sunshine Committee will send out birthday and bereavement cards to boost morale.

The marketing team needs people with experience to help reach the community. We also need people to work with Amazon Smile, which donates money to AMCSI.

Those interested people go to the AMCSI website and click on “volunteer,” or send an email to amcsibod@gmail.com.

Grants available

The board of directors have been working on ways to get funds out to our community, and they have completed two more grants. The AMC Support research grant and the adoption grant are now available. The adoption grant is intended to assist those adopting an AMCer. Go to amcsupport.org/grants to learn more.

Conference coming

The conference is quickly approaching, and with doctors Hall and Staheli speaking, you won’t want to miss it. Early bird registration is over, but you can still purchase tickets at amcsupport.org.

Remember to renew your AMC support membership for discounted prices to the conference.

Music festival set for June

The Valerie Pepe AMC Music Festival will be June 9th from 7 p.m. to 12:30 a.m. in Staten Island, New York. Tickets are $20, and kids under 12 get in for free. All proceeds go to AMC Support, Inc. Visit amcmusicfestival.com for more information.

Briefs by Lana Prater and Mark Indreika
Love at first text
A perfect couple, two lives fulfilled

Scott Braddock was tired of getting the freeze from able-bodied women who couldn’t deal with his disability. But then, one cold, February night he asked God for a sign: would he ever find a girl who could warm his heart?

The next morning, he woke to the sound of a new message on his phone. It was the answer to his prayer: a girl named Summer.
The Braddock’s marriage has been a blessing to the couple, their family, and friends. Both have arthrogryposis, but they have been undeterred by fear and doubt, living out their love to the fullest extent.

Before meeting Scott, Summer had been single her whole life. Confining to a wheelchair because of her AMC, she too had felt the sting of rejection. “I really never thought I would get any guy at all.”

Becki Reinke, Summer’s mother, explained it was hard watching her struggle emotionally. “We were equally confused as to what to do because we really couldn’t make the situation better. …We didn’t realize how empty her heart was.”

Summer, who works as a mixed-media artist, said her father always told her there was someone out there for her, but she had a hard time believing it. “I was sad, depressed, and then I met Scott.”

She read about Scott, a mechanical engineer working near Cleveland, in the AMCSI newsletter, and on that fateful morning, she decided to message him. Then her “life completely changed.”

Several days later they spoke on the telephone. “He was just so funny, and there was something about him that made me want to see him,” Summer said. They started talking every night and texting each other during the day for three weeks before their first date.

Scott said they laughed a lot. “It was fun to talk to her. It was effortless. It was like we had known each other for years.” He also said her courage impressed him, especially her decision to move, by herself, to Chicago to attend graduate school.

Both Scott and Summer have master’s degrees. Summer earned her master’s in clinical psychology and applied behavior analysis from the Chicago School of Professional Psychology in 2012, and Scott earned his M.S. in engineering from the University of Toledo in 2008.

After talking so much, Summer already felt like she knew him, and they planned a second date before even having their first. She still felt some apprehension, though. She wondered if Scott would only want to be friends after they met, especially when he saw her in her wheelchair.

She confessed she had not imagined herself dating a disabled man, and with all the care she needs, she didn’t know if a relationship was even feasible.

As she waited for Scott to arrive for their first dinner date, Summer’s cousin came over to help her get ready. “She did my makeup and curled my hair. I was so nervous because I had never been on a date before in my life. I did some shots,” she said laughing.

“I walked in and saw Summer there. Her hair was done up beautifully, and she had a big smile on her face. I felt comfortable. There were no awkward silences.” Except Scott did say he almost got knocked over by Summer’s three dogs.

Summer noticed that Scott walks just like she did when she was a child, and she immediately felt at ease.

Because Scott couldn’t drive the family van, they went on a double date with Summer’s younger sister and her boyfriend to an Italian
restaurant. "We chatted him up, asked him a bunch of questions. ...Something sparked. I pretty much fell in love with him." When Scott kissed her on the cheek that evening, she knew it was for real.

“I had an absolute blast. I was already excited about coming back,” Scott said.

“It all seemed like something out of a movie. ...We didn’t see it coming,” Reinke explained, adding

neither was Scott. He accepted the fact that Summer would need to hire caregivers, and he had no doubt they could make it work. Summer said of her family, “They have always raised me to do what you want, be what you want.”

Scott knew it was the right thing to do. “I was worried about making it feel like home.” He put in ramps, new door knobs, and he completely remodeled his bathroom, installing a roll-in shower for Summer.

Scott’s bachelor pad was full of sports stuff, and he wanted her input on how to make the place feel more homely. “I wanted her to have freedom to decorate.”

When she arrived at Scott’s house five months after they met, Summer and her family were greeted by a large bouquet of flowers.

She hired her own caregivers who come in the mornings and afternoons. Scott gets up for work at 6 am. He explained he is getting good at anticipating her needs. He helps her get up and also helps her in the bathroom before her caregiver arrives at 8 a.m.

It was a difficult adjustment at first. Scott lived by himself for six years, and he was stressed by the different

“"It all seemed like something out of a movie....We didn’t see it coming,"
Becki Reinke
Summer's mom
“She gives a good back scratching,” Scott said. “With a fork in my mouth,” she laughed.

caregivers who were coming in and out of the house, especially when they moved things out of his reach. “I was very annal about that.”

Sometimes the caregivers don’t show up, and Scott has to stay home from his engineering job. Fortunately his supervisors are understanding, he said.

They have had many other challenges as well, especially with their dog Leela, a dalmation they adopted as a puppy. Scott said it was very difficult and frustrating trying to potty train her. On one occasion, when Scott was sick, Summer decided to take the dog out herself. The leash got tangled up in her chair, and Scott had to come to the rescue.

There have been other times when Scott has fallen, and Summer has helped him. She has figured out a way to position her chair so that Scott can use her armrest to pull himself up.

She goes shopping with her caregivers, and they help around the house, making life easier, but Summer still feels bad about not being able to do more for Scott, but he will hear none of it. He doesn’t mind helping the woman he loves.

“She gives a good back scratching,” Scott said. “With a fork in my mouth,” she laughed.

“We get through it,” she said. Many people with AMC are afraid to go out on their own, or they have parents who are overprotective, she explained.

Reinke said that between her daughter’s “bullheaded” nature and Scott’s engineering skills, they have found their way.

She explained that children will fall, but that parents need to trust that someone will be there to pick them up. “Summer took a giant leap.”

The Braddocks have made a life for themselves and built up the lives of their friends and family in the process. Scott enjoys cooking, and they frequently host people at their home, throwing lavish parties.

The biggest party of their lives, though, happened on a perfect October day in 2016. They did what many would have said was impossible: they got married. When they emerged from their wedding reception that night, saluted by a host of sparkling lights held by their guests, the world welcomed the Braddocks, and it has never been quite the same.

by Mark Indreika
She's a 'dream'
AMCSI appoints Misha Walker new international ambassador

The AMC family reaches every corner of the world, and in order to better serve our entire community, the AMCSI Board of Directors has appointed a new international ambassador.

Misha Walker, who has worked tirelessly to educate people about arthrogryposis and to promote positive self-awareness within our community, has accepted the position. Walker, an AMCer who lives in Lima, Peru, started Project Dream Walker in 2012 as a way to share her story: her triumphs and struggles. As part of the project she writes a blog, produces a Youtube channel, and gives speeches.

AMCSI President Lana Prater explained, “The mission of AMCSI is to provide support for those with arthrogryposis multiplex congenita wherever they may be. As we strive to provide encouragement and information to all of our AMC families, we see the need for an additional layer of representation on an international level.”

Walker said she is happy to be part of AMCSI. She explained that she feels blessed and wants to bring more people to this “amazing family.”

As the new international ambassador, she has three goals: to build bridges between AMC organizations, spread awareness, and promote self-acceptance.

The biggest challenge will be to get consistent information about arthrogryposis out to different countries. Walker explained that if you currently Google
“arthrogryposis” in English you will get one explanation, but if you search in Spanish, you will get different information.

Walker explained that it’s difficult to get out a consistent message. Different cultures have a “this is how we do it here” mentality, and they are not open to new ideas. She emphasized the need to break the paradigms, bring people together, and build bridges.

“I want to work on different programs,” she said. There will be different campaigns matching the diverse needs of the AMC community.

“We are honored to have Misha ‘Dream’ Walker as part of the team and are excited to see what she accomplishes in this role,” Prater said. “Misha is the kind of role model we want to help spread awareness of arthrogryposis as well as encouraging self-acceptance of this unique condition.”

Walker, 33, who works professionally as an insurance and stock broker said she knew her “story could help others,” especially in helping them accept themselves.

In a recent post to her blog, Walker describes an uncomfortable time when she was 14 years old. Walker saw herself dancing on a video tape and was deeply troubled by the way she looked and moved. In fact, she was so uncomfortable she started to separate herself from her closest friends. She realized, then, that she needed to make a change, that she needed to accept herself, to love her own body.

She writes, “I decided that I was never going to be a stranger to myself ever again, I would know exactly how I move, how I look when I eat, how I sound, I would put it all out there not just for the world but for me. Everybody - including me - was going to get used to every inch of Misha.”

As part of her project, Walker has posted a number of videos showing her working through activities of daily living. She said that once AMC has been normalised, self-acceptance becomes easier.

“Since the day I was born I always heard ‘she won’t.’ But I like to contradict people, so I always did,” Walker writes on her Facebook biography.

“Now, I’ve traveled the world, lived in five countries, studied arts, have a masters degree, have dated the most good-looking guys and some of the ugliest :). I have also swam in two oceans and one sea, walked incredible beaches during the most amazing sunsets, danced till dawn, and eleven years ago, I found the love of my life, and we are happily married.

“How did I do it? I’m not afraid. I’m not afraid of what people will say; I’m not afraid to try over and over until I get it. I do things my way. Yes, I walk funny, and I call my funny walk a swing, a swing that helps me to be the girl I am. Secure. Persistent. Daring. Who just walks through the world with a smile on her face knowing that anything is possible.”

The international ambassador will serve a two-year term which can be renewed.

by Mark Indreika