Call her 'Mum'

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Seeing myself

Going to the conference in Columbus was truly the highlight of my summer. The accommodations were first-rate, the event was well organized, and the speakers gave excellent presentations. Even though the conference is an opportunity to learn new things, the most important reason is to re-establish connections with our community.

The power of sitting in the same room with 30 other adults with AMC has not been lost on me. I have found a group of people who understand my life completely, intimately. I have many disabled friends with other impairments, but it’s not the same.

Many describe our conferences as a family reunion, but it’s something even more than that to me. Our gatherings bring together a unique people, a people made beautiful by their difference, my people. The first conference I attended four years ago was truly transformative. I was overwhelmed by an intense feeling that I couldn’t immediately identify. Then, after a while, I realized what it was: I had fallen in love.

The worst part of attending the conference is having to leave, of having to go back into an able-bodied world that has been forever altered. I no longer feel that I am different from them; I feel that they are different from me. Of course I deeply cherish all of my able-bodied friends, family, and colleagues: I can’t help but feel, though, that something is missing when I am separated from my fellow AMCeers.

In all honesty, there was a time when I despised the way I look, when I couldn’t stand seeing myself on video tape. I no longer feel this way. Other than my bald spot, I now like the way I look. Going to my first meet up in Downers Grove, Illinois, I remember watching a group of children with AMC play on the floor and thinking, “My God, these are the most beautiful children I have ever seen.” And then, I literally saw myself, for the very first time, reflected in them. On page 11, I have tried my best to capture and honor this beauty in my own photography.

On page four you will be introduced to Canadian Donna Babcock who has never allowed AMC to define her. She only wishes to be remembered as a mother, as “Mum.”

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.
Music festival scores big hit

Once again hundreds of people gathered in Staten Island, New York for the 2018 AMC Music Festival, raising $5,600 for AMCSI.

The festival is the brainchild of Valerie Pepe who has worked for years raising funds and awareness about AMC. The June 9 event was once again held at Killmeyers in Staten Island.

Every year, Pepe gets on the stage at dusk and talks about her experience with AMC to raise awareness about the condition. This year she also honored Olivia Mockeridge, a child born with AMC, who passed away as an infant.

The Mockeridge family donated the volunteer t-shirts for the festival which featured "#loveLivi" on the sleeve.

Pepe said she could not do the work without her amazing team of festival volunteers.

Symposium set

The 3rd International Symposium of Arthrogryposis, to be held in Philadelphia on Sept 24-26, will be the first such meeting on AMC in the North America in a long time, or possibly ever.

The meeting is attracting practitioners and researchers from across the globe, who will share research data and treatment outcomes related to the care of peoples with AMC.

Unlike the AMCSI Annual conferences, which feature a similar roster of speakers, this meeting will be strictly a scientific meeting, where information is discussed and critiqued, in hopes of shaping the philosophies and known knowledge of the field for future development.

by Dr. Harold van Bosse

Scarman hosts events

Even though Scarman, Ward Foley, was unable to attend the conference, he has still been active.

Since the start of 2018 he has done nine Scarman events across the United States and four events in different parts of the world.

"We continue to send hundreds of dolls and coloring books around the world. The coloring book is now in print in five different languages."

In June, Foley held an event at the Paley Institute with Dr. Feldman. "It was a great honor."

Foley wishes he hadn't missed the Ohio conference, but personal circumstances made attending impossible.

There are not many streetlights on Cloverloft Court in Ottawa, Canada. If you were out for a walk late at night 20 years ago, you would have seen shadows of tall, white spruce trees and quaint, boxlike homes hidden behind leaves of silent maples.

But frequently, there would be a faint light coming from a house with blue shutters. And behind the curtain sheer of a bay window, opening into warm living room, you would have found Donna Babcock sitting in a La-Z-Boy recliner, holding a foster baby in a blanket, swaddled in warmth and love. This scene often played itself out, night after night, month after month, year after year.

Starting in 1980 and lasting for three decades, Babcock, 67, cared for 80 foster infants, many of them coming from troubled homes. As the Ottawa native gained experience and training, she was often called upon to be a "foster mum" for some of the most vulnerable children in the world: babies withdrawing from drugs, babies with fetal alcohol syndrome, babies physically abused.
“When I went to the hospital to bring home a child, I always felt a huge responsibility...leaving with someone else's baby.”

I thoroughly loved having a baby. I'd always wanted to be a mother as long as I could remember,” she said. After giving birth to three of her own children, taking in foster babies became her passion, her life's work.

She explained that caring for these infants is very important because they need the attention and love of someone specifically trained to handle their unique issues.

"I never thought I was doing anything awesome although people told me that all the time. I was just doing what I loved for the babies I loved.”

In 1974, a year after marrying her husband, Ian, she had their first child, a son named Philip. She quickly improvised a number of techniques to compensate for some of the physical limitations caused by her AMC. For example she carried him in a car seat outside of the house. This early experience helped prepare her for fostering work.

“I didn’t see that caring for babies was going to be an issue for me.” She said she wanted to work with newborns “because they are small and light.”

The Babcocks began the fostering application process in 1979. Donna said there never seemed to be much doubt about her abilities. She simply told the social worker that she just needed to do things differently.

Starting in 1980 the couple began fostering the babies of young, unwed mothers. Most of the placements were short term.

But after about five years, and some extensive training in how to handle babies with HIV, fetal alcohol syndrome, and drug dependency, she gained so much experience that the social workers began requesting her for placements.

Donna explained that the Children’s Aid Society in Canada makes foster placements. After getting a call she would go to the hospital where a nurse would tell her about the baby, many times going through the symptoms of withdrawal. The baby would be on medication to ease the symptoms. She said she never took a baby home with medication, but many of them were still withdrawing long after she started caring for them.

“When I went to the hospital to bring home a child, I always felt a huge responsibility as I would be leaving with someone else's baby. I was going in to the nursery with a social worker, but when I left, I was alone. I would go in and spend time learning what I needed to know about that particular child and spend time with that child. The nurseries always had a lot of lights and sounds, as most often it was a NICU. I rarely met the mom on
that occasion as she usually would have been discharged and didn’t hang around, especially if she knew a social worker would be coming in.”

Babies going through withdrawal are “very jittery and super sensitive to touch,” and her job was to keep them in a calming environment.

“When I am talking about jittery, I’m talking that if I put my hand on them, a very gentle touch, they would jump.” She had some babies who could not tolerate much noise. A simple sneeze could cause them great distress.

She explained that many of the babies had a very difficult time falling asleep, sometimes fussing for 22 out of every 24 hours. She needed to sit up with them at night, swaddling them to keep them from flailing. She kept a small lamp next to her living room recliner, using just enough light to see.

Donna and Ian treated the infants like their own children, taking them on family outings which would frequently be a challenge. She remembers taking some of the babies out to restaurants. “I would spend a good part of my time outside or in the lobby because they were just crying and crying and crying.”

She explained that many of the babies were either very rigid or floppy. “They were in pain, and it was pretty obvious.”

The first few days after taking a new baby home were always the most difficult. It’s hard for babies to adjust to a new environment. Eventually they would calm down and become more comfortable and relaxed, some benefiting from physiotherapy.

There were times when she had to be escorted out of the NICU with security. One baby came with a broken collarbone from an abusive home. Normally she did not allow families to visit in her home, but for this child she made an exception, allowing the grandmother to come for a visit. She said the woman was very rude, never making eye contact or saying “hello” or “goodbye.” Donna never had her come back to the house again.

“It was way harder, when after all the effort putting into a child and getting them through the worst time in their life, when they would be returned home to family. That was the absolute hardest. It was much easier to let them go if they were going for adoption because you knew at least they had a chance of being in a much more stable home than going to a home where they came from with drugs and or alcohol issues going on.

“I always loved caring for these babies and loved them as if they were my own. I always said that the day that I found it easy to let them go either for adoption or back to their family, was the day I stopped fostering.”

Ian said letting the babies go was difficult since they might be going home to a potentially abusive environment, but he got tired of being asked about it. He said they had to learn how to let things go.

Ian said Donna made many sacrifices to help so many infants. He explained that he could not always provide her much support since he was working.

Donna admitted that there was

“When I am talking about jittery, I’m talking that if I put my hand on them, a very gentle touch, they would jump.”
financial stress on the family because of the fostering. Several times they had to decide whether they could continue to afford doing it. The family received some child support from the government, but it only covered out-of-pocket expenses.

At one point, Donna took a job at a 24-hour daycare center where she worked evenings. She would take the baby with her for the first half an hour, then her husband would come on the bus after work to get the child. He would return home with the car and the baby, and then he would drive back to pick her up when she was done. He needed to bring the baby with him since he could not leave the infant at home when their own kids were sleeping.

Every time a baby left they always discussed whether to take another placement.

After she started fostering babies, Donna said her mother wanted her to quit, but she said to herself, “who’s going to do it?”

She credits her family, though. “[They have] always been and had to be supportive of us fostering, or we could not have done it.”

In 1976, 22 months after her son was born, the Babcocks had twin daughters, Lesley and Stephanie. Ian and Donna wanted additional children, but since the girls were fraternal twins, the couple was at a higher risk of having a second set, and they decided that would be too much. This prompted them to look into fostering, focusing on infants because they knew several people who were already doing it.

The Babcock’s own children grew up with the foster babies. “In their teens they were wonderful help. They were the best built-in babysitters you could get, and other people wanted them as babysitters because they knew they had all the hands-on experience,” she explained.

Her children continued to help out babysitting even after they got married, especially the two girls who still live in the Ottawa area.

Their longest fostering placement was two years, and her daughter eventually adopted the child. Donna and Ian now have three adopted grandchildren. She fostered two of them.

Eventually she retired from doing the work because she wanted more time to care for her grandchildren. “30 years and 80 babies was a good cut off.”

Ian said her AMC is part of her makeup, but it has never defined her. He said she would have done the same thing had she been born able bodied. In fact she had never even heard of the term “amyoplasia” before attending her first meet up in Ohio.

Donna’s love for babies goes back to her childhood when she enjoyed pushing them around her Ottawa neighborhood in a stroller.

She was the youngest of three children, and there was no family history of AMC. As a child Donna had several corrective surgeries. Her major surgeries were done when she was six years old.

She lived a normal childhood, going to a regular elementary school, and doesn’t remember being bullied. “I was lucky.”

She does, however, remember feeling self conscious and is still uncomfortable being stared at.

“Growing up, I never thought of myself as different. She has never liked the term “handicapped.”

Donna’s son, Philip said, “I don’t think [her] AMC impacted my life growing up at all - I didn’t grow up with a disabled mom, I just grew up with Mum.”

by Mark Indreika
AMCSI breaks attendance record at Ohio conference

Over 800 people gathered for the AMCSI Annual Conference in Columbus, Ohio, setting a new attendance record for the 13-year-old event.

The conference which ran from July 4-7 at the Easton Hilton, featured a host of different speakers and brought together AMCers from around the world. Dr. Judith Hall, a geneticist who has greatly advanced the world's understanding of AMC, gave the keynote address.

Betsy Gates-Ehlers, whose son has AMC, worked on the conference planning committee. “I was really excited to see how many first-time attendees we had.” She said there were over 250.

Justin Breen from Michigan, whose daughter has AMC, said it's hard for him not to get emotional when talking about the conference. “It's amazing to be around so many people who understand what you are going through.” He explained the simple lessons he learns from others are the best. His daughter does not have much body control, and this year they got a great idea from another family about assisting her to the bathroom which will help normalize her life.

“The lobby space was wonderful for our group.”

AMCer Gentry Burke from Texas has attended the last four conferences. He said this year’s conference was one of his favorites. He likes the conferences where there is one central location for people to socialize.

Melissa Anderson from Utah echoed Burke’s praise, saying she is drawn back year after year to see her “AMC family.”

She maintains the conference has changed her “life for the better.” Before she attended her first conference, she did not try to do many things, like helping to cook meals. After meeting other women with AMC, who have taken care of babies, she realized she was capable of doing a lot more.

First-time conference attendee
Robbie Torgerson from Wisconsin said attending the conference turned his life “upside down.” He explained he always felt like he was alone, but meeting other people with AMC was transformative, helping him get rid of many of the doubts and feelings he has had about his own life. “The connection that I made is something I know that I’ll cherish forever.”

In addition to giving the keynote address, Dr. Hall also held an informational session for attendees, and she met individually with many families. The conference also featured other medical professionals who spoke on a variety of topics.

To plan for speakers Gates-Ehlers said, “We look for doctors, therapists, and any other kind of specialist that we can think of.” The planning committee tries to get different speakers each year. She explained it’s getting harder because there are not many doctors who specialize in AMC.

Gates-Ehlers has always gotten good information from the doctors at the conference, but she has also learned a lot from talking to other families. “For me as a parent, it’s kind of a whole package. It’s not just the professional side of it.”

The conference also featured Misha Walker, an AMCeR from Peru. Walker works to promote awareness about AMC and empower AMCeRs.

Burke said he was “blown away” and inspired by her message of loving your life and living it. Walker has also helped him understand, as an AMCeR, that everything can be used as a tool.

The conference also featured a prom after the Friday banquet, and many people dressed up to show off their dancing moves.

Carly Matthews from Columbus, Georgia said dancing at the prom was the highlight for her. “I never got up and danced at any high school dances because I didn’t like people to see me dancing.”

Dr. Judith Hall headlined the conference. She delivered the keynote address, gave a separate presentation on the latest AMC research, and met privately with many families.
Linda Garcia, who is a mom of an AMCe r, said, “My happiest moment at prom was looking at my daughter dancing with joy in her eyes and seeing her feel and act like she fit in. You couldn’t stop her. Her favorite part was the photo booth.”

Five or six people typically help plan the conference every year. The planning committee begins conference calls starting in September.

Gates-Ehlers credits Michele Schaffer for doing much of the behind-the-scenes work, especially identifying conference locations two years in advance.

In order to decide on a conference location, the committee uses the following criteria: hotel availability, the size of the conference space, the number of break-out rooms, the number of rooms they have that are accessible, and the number of elevators. “It really comes down to the minutia.” Schaffer actually visits the site and measures things.

“Having done this for so long, she knows the right questions to ask,” Gates-Ehlers said.

Unfortunately, because of the unprecedented number of attendees, AMCSI was unexpectedly forced to close registration early. Gates-Ehlers emphasized it was not desirable, but nevertheless, they were pleased and surprised with the number of people.

“It was a good problem to have. We’ve gone from having 30 families at the very first conference to over 800 attendees, and that’s just amazing.”

-by Mark Indreika

Ani Samargian keeps everyone in suspense about next year’s conference at the closing ceremony. photo by Mark Indreika
Theresa paints kids to life

Artist Theresa Lucas once again hosted "Painting with Theresa" at this year's conference. She said it's one of her favorite days of the year. "I love encouraging the kids to express themselves through art whether they use their hands, feet, or mouths to hold the paintbrush. I love seeing them learn that they can do anything they put their minds to do. I can't imagine not painting with the kids. They inspire me year after year."
Chicago hospital hosts AMC family day

On May 19, approximately 60 people attended the Arthrogryposis Family Education Day at Shriners Hospital for Children in Chicago.

The day was organized by Kate Nikolai, an occupational therapist who has worked at Shriners for the past 14 years, helping many kids with AMC. Nikolai said she has always wanted to bring AMC families together to meet and share ideas.

The purpose of the event was to provide information to families about the latest medical interventions and services available to children with AMC.

“I always learned things from patients and families on tricks and little tips on how they do things at home and how they have developed ways to be independent.” Also she wanted “to share a little bit of the educational component from all of our different disciplines.” Planning for the event began last fall.

She said kids with AMC show a high degree of intelligence. “I have learned that the more you let them struggle and try to figure things out and kind of push them to be independent, that they can problem solve and figure out ways...to complete a task.”

Some families do too much for their AMC children early on which can inhibit their progress toward independence, Nikolai explained.

Dr. Shubhra Mukherjee opened the day describing the interdisciplinary team approach used by Shriners in treating children with AMC. She said that in addition to providing medical treatment and therapy, the hospital also focuses on the general well being of the child.

“When you can work all together at the same time, then you have a chance to figure out what approach would help the child most effectively,” she explained.

Dr. Kathy Zebracki, a psychologist, stressed the importance of routine screening for anxiety and depression starting at the age of 11. She said people with AMC are at a higher risk for acquiring the conditions and early intervention can help to mitigate the problem.

Margaret Chaidez, whose son Owen has AMC, spoke at the event. Chaidez works with local hospitals that help her connect with families of newborns with AMC to advise them. She said the first year is the toughest part, and that parents need to learn what works for them and how to give a voice to their child. She also explained the importance of learning how “to take time off.”

Jeffrey Mallory from Berwyn, who adopted two 8-year-old sons with AMC from China, said he learned many things. “We’ve gotten so much information that we didn’t get from just coming to the doctors’ appointments.”

Margaret Chaidez speaks about the challenges of raising a child with AMC at the AMC Family Education Day at Shriners hospital, Chicago. photo by Jane Indreika

About 60 people attended the day-long event, learning about the hospital's interdisciplinary approach to treat AMC. photo by Jane Indreika