I was blessed to have a very gifted surgeon, Dr. Hampar Kelikian, work on me when I was young. I credit the independence I have today with his skill. Sadly, many people in my generation did not have a positive experience with the medical profession. Because of botched, and many times, needless surgeries performed by poorly skilled doctors, they suffer with chronic pain. Additionally, adults with AMC are still inhibited by the stereotypes that many doctors have about disabled people, especially when it comes to quality of life issues. In recent years there have been many advances in pediatric care for children with AMC, but unfortunately, many adults have been left behind, unable to get the care they need.

This past September, however, the medical field took a step in the right direction when doctors from across the world attended the Third International Symposium on Arthrogryposis in Philadelphia. It was an important event attended by people with AMC who shared their experiences with the medical community. Hopefully, events like the symposium will increase the number of medical professionals who can work with AMCsers. In addition to doctors, we need more trained therapists who can work to improve the quality of our lives by helping more people achieve independence and their full potentials.

As people with AMC we must advocate for ourselves and for those who come after us. While AMC can have a negative impact, a diagnosis is not a tragedy: it is a challenge, a challenge for the individual, the medical community, and society in general. In addition to educating people about our abilities and advocating for greater access, we need to insist that doctors work to help us live the lives we were meant to live.

Writer Valerie Pepe traveled to the symposium in September, and she reflects on the meaning of her experience in this edition of AMC Today. This summer I interviewed Dr. Judith Hall at the conference in Columbus: you will find her profile on page 13. Finally, our cover story features Doug Moreau, the press box announcer for the New Orleans Saints. Doug has taken his love of sports to places most fans only dream of going.
Hartwick named AMCSI president

Back in August, Lana Prater announced her decision to resign as the president of AMCSI due to personal reasons. We thank her greatly for her service and time as former secretary and president of AMCSI. Best wishes!

Chris Hartwick agreed to and was voted on by the board of directors to step in and assume the role as the president of AMCSI.

Chris is an adult AMCer from South Carolina who has been on the board of directors since 2012. He has served as member-at-large, parliamentarian, and most recently, vice president. He was first introduced to AMCSI when former president, Theresa Lucas, contacted him through email after finding his information on a website. They were able to meet up with Ani Samargian, where they discussed going to the 2008 Ohio conference.

For Chris, the experience was quite surreal. “Up to that point, I had only met three others with arthrogryposis. Going to that conference was life-changing.” It was a “wow” moment for him. His love for the AMC community has grown every year. “I will do my best to be of service to the AMC community. I thank my fellow board members for having faith in me and voting me in as president of AMCSI. I am lucky to have such a great group of people to work with making this transition possible. What a great team of individuals we have to work with and advocate for the arthrogryposis community. I can’t wait to see what our future holds.”

For the past six years Chris has worked as a graphic designer for a small university. He is also a founding member of a local art gallery since 2007. Chris enjoys cooking, Legos, reading, and swimming.

Doctor opens practice

Dr. David Frumberg has opened his office to see adult patients with arthrogryposis. He specializes in pediatric orthopedics, limb lengthening, reconstructive surgery, and orthopedic surgery. His office is based in Connecticut. If you would like to make an appointment to see him, here is his information:

Dr. David Frumberg
Pediatric/Adult Ortho
Yale University
47 College Street, Room 221
New Haven, CT 06510
203.785.2579

Miss giving on Tuesday?

Even though Giving Tuesday has come and gone, it’s not too late to help AMCSI. Help us reach our goal of $10,000. Your financial gifts help us with several projects like our annual conferences, grants, mini meet ups, bereavement funds, and so many other needs. Thank you for your continued support in helping us raise awareness of arthrogryposis.

Members needed now

This year AMCSI started its membership drive on December 1. In the past it has started in January.

What? No way! Oh yes. Be the first to sign up to get a discount and early bird access to our annual conference as well as other membership perks. Membership starts as low as $10 per person.
When Michael Koenen, punter for the Atlanta Falcons, set up to receive the snap 90 seconds into the game against the New Orleans Saints, Doug Moreau, sitting inside the Superdome pressbox, focused intently on the play below. Unlike most people watching the Monday Night Football matchup in September of 2006, the first game after a year-long reconstruction project in the wake of hurricane Katrina, Doug wasn't there to celebrate, he was there to work; although he admitted feeling “goose bumps.”

Then, when Steve Gleason, safety for the Saints, broke through the line of red jerseys with his arms raised to block Koenen's punt, Doug knew he was witnessing something special.
Doug Moreau has worked as the press box announcer for the New Orleans Saints since 1998.

He said he learned the value of patience and endurance by dealing with his AMC, and this helped him get through the storm’s aftermath. Four years after the storm his new home was finally finished.

Several hundred media people cover each home game, and Doug provides them with real-time information. There are seven to eight people in the press box who just deal with statistics, and Doug is connected on headset with the head of the stat team. He is also connected with a spotter who helps him identify the players involved in each play. Inside the press box, he announces the full details of every play and gives injury updates.

In addition to working for the Saints, Doug spent 13 seasons as the stadium announcer for the New Orleans Zephyrs, a minor-league baseball team. Additionally he has worked as a sports information director at the at the University of Southwestern Louisiana (now Louisiana at La-
fayette). He completed his undergraduate communications degree from the University of New Orleans where he was sports announcer from 1986-88. Later in life he earned his teaching certificate and currently teaches at the all-boys campus of a co-ed Catholic school in New Orleans.

Working in sports helped normalize his life and distract him from his struggles caused by the hurricane. In Katrina’s aftermath he still covered the Saints games relocated to Louisiana State University’s stadium. He also worked some college basketball games, keeping a book and running the clock for Delgado Community College.

His love of sports runs in the family, starting with his grandfather who played sandlot baseball in the early 1900’s with Hall-of-Famer Mel Ott. Doug’s father coached baseball for years, and his two older brothers became successful college athletes: David played baseball at Northeast Louisiana University, and Daryl played basketball at Tulane University.

Because of his AMC, Doug did not play organized sports except for wiffleball when he was really little. However, the coaches on his brothers’ teams always included him, working as a basketball equipment manager or as a batboy. “They always had me involved on my brothers’ teams.”

His announcing career began when he was about 11 years old. His father coached baseball in a Babe Ruth League where his brothers played. The kids played in a huge high school stadium, 340’ down the lines, too big for even major leaguers. The games were covered by members of the local media who sat in a wooden press box behind the grandstand. Doug, who worked as a batboy, frequently climbed into the pressbox and asked the announcer if he could announce his brother’s name before his at bats.

At the time there were six games a day, and one day in the spring of 1973, the announcer asked Doug if he could take over and keep score for one of the games. They said, “You know how to do this,” and that’s how his announcing career began.

When he wasn’t announcing, he always played outside with his brothers. They played a game called run down. It was great exercise, helping Doug build his lateral movement. The kids had another baseball game called hit the cable.
It was played with a rubber ball. The batter would throw the ball at a telephone wire. If his opponent caught the ball it was an out. If it hit the ground it was a hit. The batter would keep playing until he made three outs.

Also, he remembers watching his brother’s play football in the neighborhood, sitting against a tree listening to Notre Dame football on the radio, keeping everyone up-to-date on the score. After the game was over, and the other boys left, his brothers would stay and play with Doug. Even when he got tired they made him continue. “They would say, ‘You don’t quit until we do.’”

In the early 80’s, when his brother David became a high school baseball coach, he asked Doug to announce the games. He would bring his speakers and mixing board to the field. He started mixing in music when other people weren’t doing it.

His father coached baseball at the college and high school levels, and for a while Doug worked with him as an assistant. Later in life, after his first hip replacement, he begin working with a youth athletic program run out of a Catholic school. His boss, Firmin Simms, was a coaching legend and one of Doug’s childhood idols. He was “another dad in my life.”

He began working in the Sugar Bowl in 1988, and he became the press box announcer in 1995. In 1993, he became the press box announcer and sports information director for Tulane University. A friend, who was working as the sports information director at the school, was contacted by the Saints when they were looking for a new press box announcer; he recommended Doug who did not even have to audition since he was so well known in the New Orleans sports community. “It was the merit of the work people had seen me do over the years.”

He said the Saints’ organization has fully embraced him, and he has become friends with legends like Hokie Gajan, who played for the Saints in the 80’s. He also has a professional acquaintance with Saints former running back and current radio analyst Deuce McAllister. He has also become acquainted with Bobby Hebert, a former Saints quarterback who does a post-game radio show. Doug takes detailed notes on the
game, and because he is so knowledgeable, he often shares his insights on obscure moments in the game with Herbert before his does his show.

He frequently talks football with the guys who have been in the locker room and has been in team meetings. They don’t treat him like a fan, or even an announcer, they treat him as “an understander” of the game, he explained.

He credits his mother, who recently turned 83, with much of his success. Doug was born in 1962, and the first orthopedic doctor she met explained AMC and then proceeded to outline all of things Doug wouldn’t be able to do in life: it wasn’t what she wanted to hear.

“My mom stood up to him.” She made the doctor agree to keep working with Doug as long as progress was being made: Doug exceeded all of that doctor’s expectations, spending the first seven to eight months of his life in the hospital. She stayed with him 24 hours a day, sleeping in a hospital chair by his bedside. She actually helped the overnight residents at the hospital, holding out Doug’s arms as they casted and then recasted them because he was growing so quickly and his bones were so pliable.

As he grew Doug’s mom helped him learn how to pick things up, like jar lids, slowly increasing the weight of each lid over time. It was “my earliest weightlifting.” He said when people see how active he is today, “They can’t imagine what it was like when I was an infant. They don’t understand how much work was put into me.” He calls his mother “a wonder,” and he said she still is.

After the hurricane she had just turned 70, but that did not stop her from doing what needed to be done. Fortunately she only had an inch and a half of water in her home, but there was a mess to clean up, so she put on heavy gloves and started scrubbing mold off of the floors and walls. It was her “it’s time to get to work” approach to life that got her through the ordeal, he said.

Clearly Doug Moreau has taken the same attitude about life, and when, on that fateful Monday night, he watched a golden-helmeted Curtis Deloatch chase down that blocked punt as it bounced into the endzone to score the team’s first touchdown, he must have smiled as he listened to the Superdome erupt. He knew that New Orleans was back, and so was he.

“He said when people see how active he is today, ‘They can’t imagine what it was like when I was an infant. They don’t understand how much work was put into me.’”

by Mark Indreika
Some of my friends wondered why I was so interested in attending the 3rd International Arthrogryposis Symposium in late September, 2018. You were born with AMC, what more can you possibly learn, they asked. As it turned out, quite a lot, not only about the trajectory of my struggle with AMC, but about my role within the community as an advocate.

I couldn’t sleep the night before traveling to Philadelphia. I tossed and turned; I turned on the light; I wrote down questions to ask the experts from fifteen countries who would be attending the symposium.

I had recently turned 50 and getting older as an AMCer has its special challenges requiring consideration from the medical profession: 1. How can we manage intensifying arthritis as we age? 2. What happens when we go through menopause? 3. What about the prohibitive cost of medical equipment to help us live independently in our golden years? This is just a sampling of my concerns, of course.

I checked into the Hilton at Penn’s Landing the night before; I wanted to be on time in the morning for the first session. Getting dressed takes organization and energy, so I put out my clothes the night before: a skirt, a nice top and thin black cardigan. I went to have breakfast and made my way to the ballroom. It was brightly lit; a golden chandelier hung from the center of the ceiling. I walked slowly on my crutches, as I must. But I was also deep in thought. I would be in the presence of “experts.” I believe that we always have a lot to learn from each other, but would they hear my questions and see me and other AMCers present as more than bodies to be operated on?

The room had rows of chairs that would seat nearly three hundred people as well as three rows of long tables draped with dark-blue table linens. I needed a table because I planned on taking notes, a lot of notes. I took a seat on the left side of the audience in the third row. I placed my notebook, pens and symposium materials on the table and my two crutches behind me on the floor along with my handbag and tote bag. I took my seat and looked around. Many languages were being spoken, but the lingua franca was Arthrogryposis Multiplex Congenita.
Dr. Harold Van Bosse, one of America’s most recognized orthopedic AMC surgeons, was the first speaker. His lecture was technical and difficult. I could hardly spell most of the words he used and felt as though I was in medical school. But I persisted, as I always do. I could always look up the words he used on the internet, I thought.

We were a strange mix of people—some with and some without AMC—all together at one conference. It was a first for me and a bit intimidating, even overwhelming. I wondered why the presentations were not in lay terms also, which would have made them accessible to everyone.

More lectures, more information. And then something quite strange and upsetting surfaced, a fact I understood loud and clear: more cases of AMC are treated in Europe and Russia than in America. Why? Are there more cases in Europe and Russia? Is AMC overlooked and ignored in the United States?

I regained my composure during a description of recent advances in open-hip reduction surgery. I had had this procedure; there are photos of me in a body cast and stories of how my parents cared for me during this time. I must have suffered a lot in that cast. As the doctors on the panel explained the new casting procedure, I felt hopeful. Children born today with AMC might have an easier time, I thought. But I also had questions. Do we always have to opt for surgery? What will happen to us if we don’t, especially as adults?

The attendees were given the opportunity to ask questions or make comments after each segment. I was hesitant to go to the microphone, which is not like me, maybe because I was surrounded by people who know a lot more than I do about AMC, from a medical perspective anyway. Finally, I said to myself: I need to say something about my hip reduction surgery and hope it comes out right. I took a deep breath and headed to the microphone at the front of the aisle near where I was sitting. I got in line and waited my turn. I was grateful that my friend, Marty Sheedy, spoke first. He explained to the panel that his doctors recommended not to have his hips corrected. He demonstrated how he walks with a scissor gate; he doesn’t have pain.
and feels more comfortable walking this way. There was a warm sound of laughter, an acknowledgement that some AMCers don’t need such a procedure and that parents and young adults, certainly, can demonstrate how they cope emotionally as well as physically as they weigh options and make their own decisions. Hypothetically, a new procedure is great, but there are many factors to consider before opting for advancements in technologies.

Marty made his way back to his seat, and then it was my turn. I took another deep breath and adjusted the microphone. “Good Morning and thank you for the opportunity to let me share my story,” I said. “My name is Valerie Pepe, and I live and work in New York City.” Then I told the panel that I had had an open hip reduction in 1969, giving my age away. A chuckle from the crowd was heard.

“I was in a body cast for six months,” I continued.

There was a look of shock or, perhaps, amazement. “I don’t even have an orthopedist who fully understands AMC,” I said. “Who here among you will address the needs I now face as an adult? Once we are operated on as children, we are still not fine; you cannot forget us. We require care and monitoring into our adulthood and old age. Are any of you caring for adult AMCers?”

Though only one of the panel members, Dr. Czubak Jarek from Poland, could answer my question affirmatively, they all agreed that I was right: adult AMCers also require care. Little did I know at the time that Dr. Jarek would be honored at the dinner reception. By then, I had already bumped into him and his wife. “I would like to speak to you after dinner,” he said.

I was thrilled. What an opportunity! “Of course I would like that,” I told him.

He wanted to know what I did for a living. I explained my educational background and how I had changed careers to work in the field of energy for the City of New York. He was impressed by my work schedule, as am I some days. I told him I was a freelance writer, too.

The next day I gave him a signed copy of my memoir, Deformed; My Remarkable Life, which has become an educational tool both for AMCers, friends, families, colleagues, and physicians. I even joked that if he liked it, I’d try to get it translated into Polish. We exchanged emails and promised to keep in touch.

The conversation with Dr. Jarek, his wife and some of his colleagues was only one of many I had at the conference, most of them after the sessions were over. I was thinking a lot about my aging self, and though I agree, of course, that the earlier the diagnosis the better it is for the child so that he or she can become a fully functioning...
adult, our needs do not end as we become young adults and adults.

And there’s another issue: doctors, by definition, are healers. And surgeons, in particular, are eager to achieve a kind of perfection in the operating theater. This is both unrealistic and unfair to the AMC patient. If an AMCer expects perfection, s/he will be disappointed.

I have had so many surgeries; I am able to walk, to work, to have boyfriends, to travel. I live a full and interesting life, but I still need crutches, I still wear special shoes and have a lot of issues related to the use of crutches, for example. My hands are arthritic. In other words, I struggle every day of my life and transcend the struggle every day of my life because I am mature enough and experienced enough to realize that I have to meet my doctors’ efforts halfway. They are not miracle workers. They make repairs, but it’s up to the individual to keep the repair working. Certainly, I expect functionality: toes that wiggle, a correction to my feet to make walking easier, paratransit to get to work. But beyond that, it’s my responsibility to live the life I want to live.

By the end of the conference, I had renewed my determination to advocate for AMCers and also to attend more medical conferences. I was pleased that I’d found the courage that day to walk up to the microphone. The dedicated doctors wanted to hear our stories; that is why we had been invited. It was a life-changing experience for me and, I hope, for them as well. I haven’t reached out to my new friends from Poland yet, but I plan to do so soon.
When Dr. Judith Hall came across her first case of AMC at the genetics clinic she started in Seattle in the 1970s, she did not know much about the condition, and as it turned out, neither did many other doctors. Thousands of cases later, she has established herself as the world’s foremost expert explaining the different types and causes of AMC.

Over the years, continuing into her retirement, she has devoted much of her career to identifying and categorizing the different types of AMC: the muscle, nerve, myelin, (etc.) variants. Currently researchers are studying the genetic pathways associated with the condition.

“It has been a 40-year journey, to really be able to say, we are now at a stage where we can start to seriously think about treating genetic types of AMC,” she told AMC Today at this summer’s conference in Columbus, Ohio.

After seeing her first case of AMC, she began the research process. “I went to the medical literature, and everything was about babies who died with arthrogryposis.” She sent her students to the Shriners in Spokane and Portland to gather all of the cases of arthrogryposis. Then she went through the records of the Seattle Children’s Hospital. They started with 1000 records and then whittled them down to 300. “That’s when we really got a handle on the different types of arthrogryposis.”

Early on she began a collaboration with orthopedist Dr. Lynn Staheli. Together they worked for eight years to develop an arthrogryposis clinic at the children’s hospital in Seattle.

It was the first clinic to establish a multidisciplinary treatment approach. “We learned a huge amount.” By the late 1970s “We could separate Amyoplasia from other types.” They also discovered that all the types were related to not moving early during the pregnancy.
She explained that in the late 1990s their clinical work inspired them to write *Arthrogryposis: A Text Atlas*, one of the earliest and most definitive medical books on the condition which is still relevant today.

Dr. Harold Van Bosse calls Dr. Hall “the grande dame” of AMC. “She is probably the person who single handedly has done the most for our understanding of arthrogryposis, not just in genetics but also working hard to get people to come together to share thoughts on arthrogryposis, to share thoughts on treatment and natural history of these children.”

Calling her “an intellectual partner,” he said her work has given him a more rounded understanding of AMC beyond an orthopedic perspective, allowing him to communicate much more information to parents.

During her career, she has seen 7000 cases of AMC, 20% of them being consults. As a geneticist, she has especially been interested in studying the family histories of those affected.

She has been retired for 15 years, but she is still active, meeting with families, finding out all the available information, keeping up with the literature, and getting that information out there, explained Dr. Van Bosse.

Dr. Hall is especially interested in studying contractures and the amount muscle associated with each of them. In 2000, the human genome project started. They have since identified over 400 genes which, when mutated, lead to AMC.

“We are thinking in terms of these pathways, how do you think about getting around what’s missing.” Understanding these pathways will be key to formulating effective treatment options.

She says many adults with AMC want to know if they have a genetic version of AMC, especially if they are planning to have their own families. “They are always worried about whether it might be worse” for their own children.

She says that the medical field doesn’t know much about adults with AMC, and she said that’s why the international on-line adult registry started in Canada is so important. She said doctors need to know what happens to adults with AMC as they age. Dr. Bonnie Sawatzky, Associate Professor in the Department of Orthopaedics at the University of British Columbia, is spearheading the project. Dr. Sawatzky, who has AMC herself, was a patient of Dr. Hall’s.

Born in Boston and growing up in Seattle, Dr. Hall got interested in genetics as a student at Wellesley College where “an old maid biology teacher” introduced her to the field.

She credits her admission to medical school because of her interest in genetics, explaining she thinks she might have been accepted at the University of Washington because she answered a question correctly about the number of human chromosomes on her entrance exam.

Eventually she returned to Seattle where she started medical genetics clinics all over the northwest. She then moved to Vancouver in 1981 where she was in charge of genetics until 1990 when she became chairperson of pediatrics. She retired in 2004.

“I have always loved arthrogryposis. It is such an interesting challenge to understand, and the families are so wonderful, so I kept being involved.”

*by Mark Indreika*

---

**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.