2026 OFFICIAL CONFERENCE PROGRAM

21ST ANNUAL ARTHROGRYPOSIS MULTIPLEX CONGENITA SUPPORT CONFERENCE

COLUMBUS, OHIO

JULY 1-4, 2026

Celebrating 21 years with our AMC family!

AMCSI

Arthrogryposis Multiplex Congenita Support, Inc.

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ALEXIS RECORD

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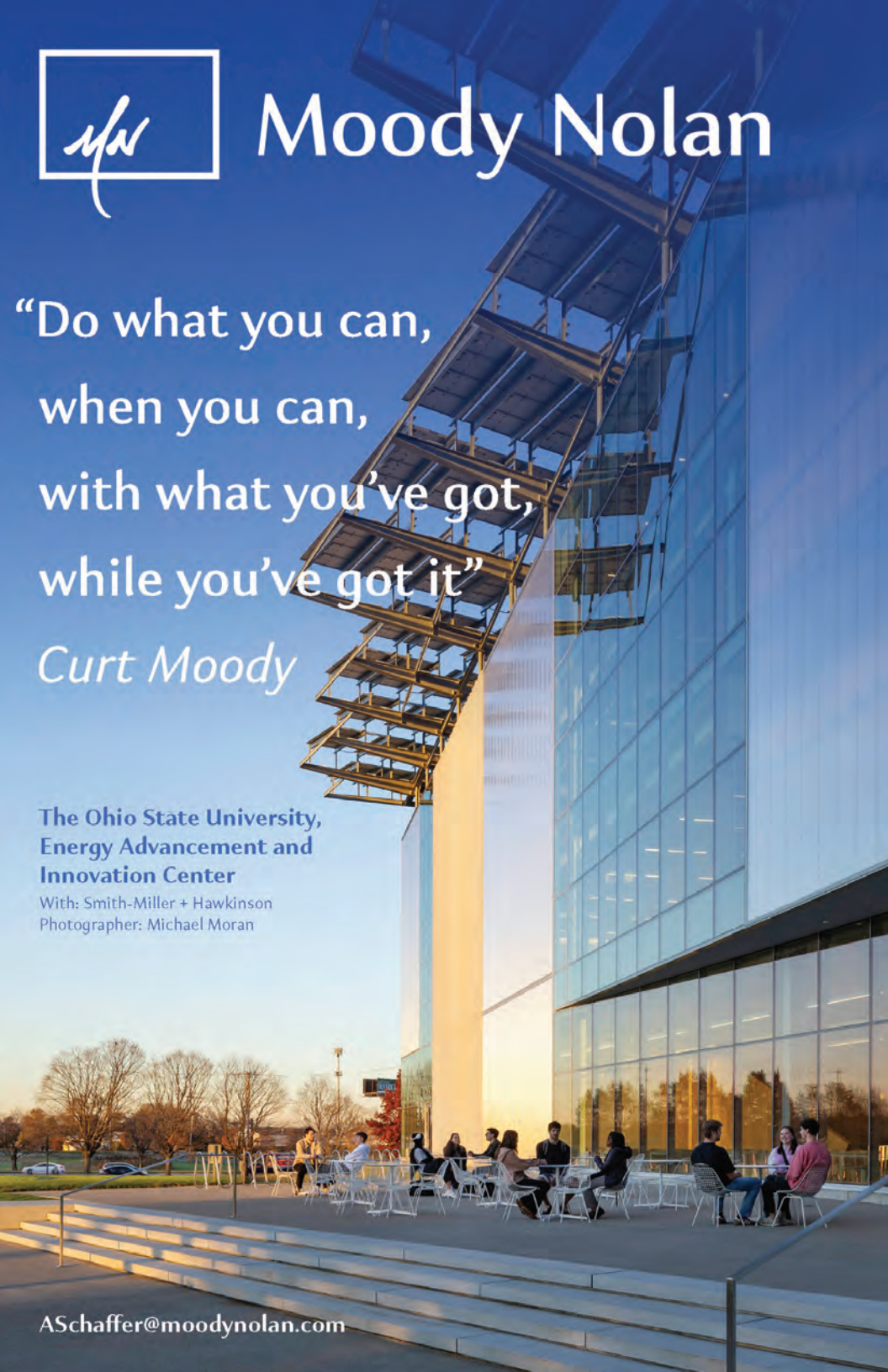
Moody Nolan
"Do what you can,
when you can,
with what you've got,
while you've got it"
Curt Moody
The Ohio State University,
Energy Advancement and
Innovation Center
With: Smith-Miller + Hawkinson
Photographer: Michael Moran
ASchaffer@moodynolan.com

LETTER FROM ALEXIS

Dear AMC Family,

Welcome to the 21st annual AMCSI Conference! I want to take a moment to say how grateful I am that you are here.

Every year, I think I know what our conference is about. I tell myself it's the workshops, the speakers, the children's programming, the late-night conversations, the laughter echoing down hotel hallways, or the endless hunt for coffee before the first session of the day. And every year, I'm reminded that it's really about the people.

What started as a gathering of a few families has become something extraordinary, a community that stretches across states, countries, and generations. Some of you are attending for the first time. Others have been with us since the beginning. No matter when you joined us, you're part of the story now. Hey fam!

Over the next few days, I hope you'll learn something new, reconnect with old friends, make new ones, and find a few moments that remind you why this community matters so much. I also hope you'll extend a little grace to our volunteers and planning team who have spent months turning spreadsheets, emails, and caffeine into the event you're about to experience.

A few practical reminders:

- Wear your name tag. It's your ticket to workshops, activities, and helping the rest of us remember names.
- Introduce yourself to someone you don't know yet.
- Take lots of pictures.
- Stay flexible when the occasional bit of conference chaos appears. (It's not a bug; it's a longstanding tradition!)

Thank you for being here and for helping make this gathering what it is. Whether this is your first conference or your twenty-first, we're excited to spend these next few days with you.

Now go have fun, we've been planning all year for this.

Welcome to Conference!
Alexis Record ~ *President | AMCSI*

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LETTER FROM ANI

Dear AMC Family,

Welcome to the 21st Annual AMCSI Conference. Whether this is your first time joining us or your twenty-first, we are so glad you are here as we come together to celebrate more than two decades of connection, growth, and shared hope.

Twenty-one years ago, AMCSI began with a simple but powerful purpose: to make sure that no family facing a diagnosis of arthrogryposis would ever feel alone. What started as a small circle of parents and caregivers has grown into a vibrant, compassionate, and strong community built on care, understanding, and shared experience.

This conference, and everything we have built together, would not be possible without our dedicated medical partners. To the doctors, therapists, surgeons, researchers, and clinicians who devote their work to understanding, treating, and supporting individuals with AMC, thank you. Your commitment not only advances research and care, but it also directly changes lives. We are especially grateful to the researchers who continue to pursue new insights into arthrogryposis and expand what is possible for our families.

We also want to share how deeply important your support is in sustaining AMCSI. This organization exists because of the generosity of our community. Donations are not just helpful, they are essential. They directly power the programs that serve families year-round, including grants, scholarships, mini-meetups, research initiatives, and conferences like this one. Without this support, these opportunities for connection, education, and care simply would not be possible. Every contribution helps ensure that families can access resources, build community, and continue moving forward with support behind them.

I also want to recognize the many board members, committee leaders, and volunteers, past and present, who have given so much of their time and energy to AMCSI. Your dedication has built the foundation we stand on today. Because of you, this community continues to grow, connect, and support families around the world.

And to our extraordinary Conference Committee, lovingly known as “the Loons,” there are truly no words big enough to capture our gratitude. For 21 years, you have given your time, heart, and energy without expectation, working behind the scenes to create a space filled with joy, care, and connection. Year after year, you bring this conference to life with remarkable attention to detail and unwavering commitment. We simply could not do this without you.

As we look ahead, we carry forward 21 years of strength, stories, and support, along with a shared belief in what we can continue to build together.

Here is to everything we have accomplished, and to all that is still to come.

With all my heart,

Ani Samargian ~ *Founder*
Community Support Advocate

LETTER FROM THE PLANNING COMMITTEE

Dear Friends,

The Conference Planning Team (also known as the Loon Crew) is excited to welcome you to the 21st Annual Arthrogryposis Multiplex Congenita Support, Inc. conference!

Whether this is your first time joining us or you are a returning attendee, we are glad you are here. First time attendees, welcome. Returning families and friends, welcome back. This community continues to grow stronger because of the people in it, and we are grateful you are part of it.

We would like to extend a sincere thank you to all of our volunteers. This conference simply would not be possible without your time, energy, and willingness to step in wherever needed. We can plan, but it is the volunteers who bring everything to life. Thank you for making this event happen.

Over the next several days, you will have the opportunity to participate in a wide range of educational and support sessions. We are grateful to all of our presenters who volunteer their time, expertise, and travel to be here. Please be mindful that many speakers have tight schedules and may need to depart promptly after their sessions.

We also want to make this conference as comfortable and supportive as possible for every family. Please feel free to take breaks as needed, step out of sessions when you need to, or choose the activities that best fit your needs. There is no right or wrong way to experience the conference, and we encourage you to take care of yourself and your family throughout the weekend.

After the conference concludes, please watch for an email sent to the address used during registration. This will include a survey link. We truly value your feedback and use it to help guide and improve future conferences.

If you are interested in joining the Loon Crew, we would love to hear from you. Please reach out to any member of the team. We are always happy to welcome new helping hands.

Welcome to Columbus!
The Loon Crew

Vice-President of Programming

Maureen Goede

Beth Sellers

Betsy Gates-Ehlers

Jan Shea

Larina Swanson-Carter

Ana Van Bosse

KEYNOTE SPEAKER - Todd Craighead

Bio: Born and raised in Stillwater, Oklahoma, Todd has degrees in Wildlife Conservation and Communications from Oklahoma State University. He has worked as a nature instructor at a children's camp on the shore of Lake Superior, and a ranger with the U.S. Forest Service in Colorado. He then retired in 2025 after 30 years with the Oklahoma Department of Wildlife Conservation as producer and host of the award-winning television show, Outdoor Oklahoma. Currently, Todd is living out his childhood dream as a Ranger in Yellowstone National Park. His passions include hunting, camping, rock crawling in his 1980 Jeep CJ7, and his daughter Emily.

Thursday, July 2nd | 10:00 AM - 10:45 AM | Opening Ceremony | Easton A & B

Bio: Philip F. Giampietro, MD, PhD, is currently the Asok K. Ray, M.D. FRCS (EDIN) and Purnima Ray Endowed Professor of Pediatrics and Section Chief of Medical Genetics in the Department of Pediatrics at University of Illinois-Chicago School of Medicine. He received his B.S. in Biological Sciences at State University of New York at Stony Brook, Doctorate in Biomedical Sciences at the City University of New York and M.D. at the State University of New York at Stony Brook. Dr. Giampietro completed his internship in Pediatrics at the State University of New York at Stony Brook, a residency in Pediatrics at Long Island Jewish Medical Center, and a Fellowship in Medical Genetics at Weil Medical College of Cornell University. Throughout his career, he has been active in the education of medical students, genetic counseling students, physician assistants, and pediatric residents and fellows. Prior to his current position, Dr. Giampietro held positions at Rutgers -Robert Wood Johnson Medical School, Drexel University College of Medicine, University of Wisconsin- Madison, Marshfield Clinic, Marshfield Clinic and Weil Medical College of Cornell University. Dr. Giampietro's research interests include dysmorphology and birth defects, in particular the genetics of congenital and idiopathic scoliosis. He has worked closely with orthopedic surgical colleagues, clinical and molecular geneticists, and epidemiologists to better understand genetic and environmental contributions to these conditions.

Session topic: What Is A Genetic Evaluation And How Will It Benefit My Child?
Session Description: In this session we will review the nuts and bolts of a genetic evaluation in the context of arthrogryposis multiplex congenita. We will discuss the components of a genetic evaluation including what historical and physical examination findings are important. The different types of genetic testing utilized in clinical practice and types of results which are expected along with limitations of testing will be highlighted. We will discuss categories of genes found to be associated with AMC. The process of genetic counseling will also be discussed.

Thursday, July 2nd | 11:15 AM - 12:00 PM | Genetics | Location Easton A

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SPEAKER SESSIONS

SCAN FOR THE MOST UP-TO-DATE SPEAKER SCHEDULE

Bio: Ms. Kimberly Kolstad is a full-time medical social worker at Craig H Neilsen Rehab Hospital at the University of Utah. For over 18 years she has been advocating for underprivileged individuals and most recently has had the opportunity to work with individuals with spinal cord injuries, amputations, and transplants. Kim has successfully created and runs a peer coaching program for patients with new spinal cord injuries. She works closely with TRAILS Adaptive Sports and has organized an event for Veterans with complex disabilities to experience the Tetra Watercraft. Kim has a love of adventure, and over the last two and a half years, her life has been changed for the better by participating in over 15 different adaptive sports, her favorites being snow skiing with the TetraSki, wake-surfing, and adaptive mountain biking. As a social worker and a person with AMC, Kim knows the importance of accessibility and inclusion for all. She is now advocating for adaptive sports to be known and accessible to all people with disabilities, especially those with AMC.

Session topic: Different Gear, Same Soul: Maintaining Identity Through The "Off-Season."
Session Description: What happens when the thing that defines you is suddenly taken away? This powerful session dives into the identity crisis that follows injury, illness, or life disruption—and the often-unspoken grief of losing not just an activity, but a sense of self. Blending raw personal experience with clinical insight, we will challenge the idea that we are what we do, and instead reframe identity as something deeper, more resilient, and adaptable. Through adaptive sport and community connection, attendees will explore how to stay grounded in who they are—even when everything familiar shifts. Because identity doesn't have an off-season—it evolve

Thursday, July 2nd | 11:15 AM - 12:00 PM | Adaptive Sports | Easton B

Bio: Dr. Lauren C. Hyer, M.D. joined Shriners Children's in Greenville, SC in 2016. Since then she has She primarily cares for lower extremity differences in children with arthrogryposis. She embraces a multidisciplinary model involving therapy, motion analysis, orthotics, and orthopedics. Her primary research interests involve understanding and improving mobility as well as enhancing functional independence for children and youth with arthrogryposis.

Session topic: Discussing Foot Conditions In Arthrogryposis
Session Description: During this session Dr. Hyer will be discussing foot conditions in arthrogryposis. From clubfoot to congenital vertical talus, and everything in between, we will walk through what treatment looks like from infancy to adulthood.

Thursday, July 2nd | 2:00 PM - 2:45 PM | Feet | Location: Easton A

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Bio: Ms. Tammy Phipps is an Occupational Therapist (OT) and Certified Driver Rehabilitation Center of Excellence CDRS. She has been practicing in the area of driver rehab for over 20 years, starting her first program at a hospital in Aberdeen, SD (2005). She deployed to Iraq in support of Operation Iraqi Freedom from June 2007-June 2008, while in Iraq MAJ (then CPT) Phipps was recruited to create the driving rehab program at the Department of Defense's largest amputee care rehabilitation facility, Walter Reed Army Medical Center in Washington DC. She developed (2008-2016) and led the first comprehensive driving rehabilitation program in the Department of Defense. During her tenure she provided driving rehab services to over 600 military service members with limb-loss, traumatic brain injury, post-traumatic stress and anxiety, paralysis, burns, visual deficits and complex poly-trauma. The complex nature of the illnesses and injuries seen required her to be extremely innovative as "out of the box solutions" were not going to work. Her experience at Walter Reed provided her the unique perspective needed to start private practice. In August 2016, Tammy opened Driver Rehabilitation Center of Excellence, LLC (DRCE) in Chantilly V A. Her business combines driver rehabilitation and vehicle modifications all in one shop. She has recently expanded driver rehabilitation centers in Richmond V A and Columbus OH. She currently employs 13 driver rehab specialists whose common goal is to make community mobility / driving accessible to as many as they can reach.

Session topic: Driving Rehab Solutions, Featuring Cases Where AMC Was The Primary Diagnosis
Session Description: This session explores how individuals with Arthrogryposis Multiplex Congenita (AMC) can achieve independence with driving through working with a Certified Driver Rehabilitation Specialist. Planning can often begin early, and we will explain the comprehensive driving evaluation. Attendees will see a variety of case studies showcasing customized vehicle modifications. Attendees will gain insight into the full spectrum of adaptive driving solutions, ranging from low-tech to advanced high-tech steering and braking systems.

Thursday, July 2nd | 2:00 PM - 2:45 PM | Driver Rehabilitation | Location: Easton B

Bio: Dr. Lisa V Wagner DHS, OTR/L, has a dedication for all things AMC! She loves engaging with people both on a clinical and a research level. This work has resulted in peer-review articles, book chapters and the ability to speak nationally and internationally. Passionate about children with AMC, she is currently collaborating on an outcome assessment for better understanding of the upper extremities, knowledge dissemination of rehabilitation guidelines and defining AMC classifications for better understanding across disciplines.

Session topic: Adventures In Autonomy
Session Description: We all strive for autonomy and independence, but what does this look like in our real day-to-day lives? For AMC, independence has multiple layers. In this session, we will consider the balance of self-awareness, adaptive equipment, social considerations and more in our quest to be independent people living in an ever more connected world. Come ready to share and discuss your quest for autonomy.

Thursday, July 2nd | 3:00 PM - 3:45 PM | Autonomy | Location: Easton A

SPEAKER SESSIONS

SCAN FOR THE MOST UP-TO-DATE SPEAKER SCHEDULE

Bio: Dr. Reid Nichols, M.D., FAOA, FAAOS, is a pediatric orthopaedic surgeon at Nemours Children's Health, Delaware Valley, and Assistant Professor of Orthopedic Surgery, at Thomas Jefferson University. She received her undergraduate degrees from the University of Virginia and from Johns Hopkins University School of Nursing. She earned her medical degree from Northeastern Ohio University's College of Medicine. After graduating from residency in orthopaedic surgery at Maimonides Medical Center in Brooklyn, NY, she completed a limb lengthening and reconstruction fellowship at the International Center for Limb Deformity in Baltimore, MD. Under the supervision of John Herzenberg, M.D., she received advanced training in the management of clubfeet. She received advanced training in pediatric orthopaedics after completing a fellowship at the Nemours/Alfred I. duPont Hospital for Children. She is currently the president of the Limb Lengthening and Reconstruction Society(LLRS). She is active in many societies, including the Pediatric Society of North America, LLRS, American Academy of Orthopaedic Surgeons, American Orthopedic Association, and the Ruth Jackson Orthopaedic Society. She has served as the BOS representative for LLRS and is currently the POSNA BOS representative. Dr. Nichols' clinical interests include limb deformity and reconstruction, clubfoot, arthrogryposis, and pediatric trauma. She serves as the director of the Clubfoot Clinic and co-director of the Arthrogryposis Clinic.

Session topic: Focused On The Arthrogrypotic Hip For Michigan, Go Blue!
Session Description: This session focused on the arthrogrypotic hip, reviewing the unique anatomical and functional challenges associated with hip involvement in arthrogryposis. Discussion included clinical assessment of hip motion, stability, gait, pelvic alignment, and the impact of associated contractures on overall mobility and function. Relevant anatomy was reviewed, including soft tissue contractures, muscle imbalance, acetabular development, and the presence of unilateral or bilateral hip dislocation commonly seen in these patients. Treatment options were explored based on patient age, functional goals, and severity of deformity, ranging from conservative management and physical therapy to surgical interventions such as soft tissue releases, osteotomies, and hip reduction procedures. Emphasis was placed on individualized decision-making and balancing hip stability with preservation of mobility and functional independence.

Thursday, July 2nd | 3:00 PM - 3:45 PM | Hip | Location: Easton B

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SCAN FOR THE MOST UP-TO-DATE SPEAKER SCHEDULE

SPEAKER SESSIONS

Bio: Dr. Kaveh Asadi-Moghaddam, MD, PhD, FAANS is a board-certified pediatric and adult neurosurgeon serving as Director of the Spasticity Center at the Paley Orthopedic & Spine Institute and Director of Pediatric Neurosurgery at Palm Beach Children's Hospital in West Palm Beach, Florida. He specializes in complex neurosurgical care including pediatric neurosurgery, trauma, and neuro-oncology, with prior leadership roles at AdventHealth for Children and Helen DeVos Children's Hospital. Dr. Asadi-Moghaddam completed his medical and doctoral training in Germany and neurosurgical training at The Ohio State University and Cincinnati Children's Hospital, and remains active in research, clinical trials, and national neurosurgical organizations.

Session Topic: A Tethered Cord Spinal Cord
Session Description: A tethered cord spinal cord can contribute to weakness, imbalance, pain, and progressive deformity. When the spinal cord is under chronic tension, orthopedic correction alone may not lead to durable functional improvement. This session will highlight when to suspect a tethered cord and why a spine MRI evaluation is important in patients with AMC.

Thursday, July 2nd | 4:00 PM - 4:45 PM | Spine | Location: Easton A

Bio: Dr. Fran Guardo, MEd, MPT, DPT, BSPTS C1&2 Director of Rehabilitation for the Paley Orthopedic and Spine Institute (POSI) since 2009. She is a sought-after speaker in the field of Rehabilitation of Limb Lengthening and Treatment of Arthrogryposis, where she trains therapists and surgeons internationally. She has authored multiple book chapters, presents nationally and internationally, and is an adjunct professor for Nova Southeastern University, where she lectures in the Physical Therapy Department.

Session Topic: Early Intervention And Beyond.
Session Description: In this session, participants will learn about the variety of options available for infants and the subsequent interventions recommended as children age. We will discuss surgical options and the rehabilitation techniques employed to unlock and restore motion in various situations.

Thursday, July 2nd | 4:00 PM - 4:45 PM | Interventions | Location: Easton B

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SPEAKER SESSIONS

SCAN FOR THE MOST UP-TO-DATE SPEAKER SCHEDULE

Bio: In 2015, **Dr. David Feldman** joined the Paley Institute to lead our new Spine Deformity Center and Hip Pain Center. Dr. Feldman was previously Professor of Orthopedic Surgery and Pediatrics as well as Chief of Pediatric Orthopedic Surgery NYU Langone Medical Center/ NYU Hospital for Joint Diseases. Dr. Feldman specializes in pediatric orthopedic surgery and subspecializes in children with scoliosis and severe limb and hip deformities. As well, he focuses his practice on conditions such as arthrogryposis, Multiple Hereditary Exostosis and Skeletal Dysplasias. After graduating from the Albert Einstein School of Medicine in 1988, Dr. Feldman interned in general surgery at NYU Langone Medical Center. He completed his residency in orthopedic surgery in June 1993 and spent the next year in fellowship at The Hospital for Sick Children Toronto with a special interest in pediatric orthopedic surgery and pediatric spine surgery. Dr. Feldman brings over 25 years of experience in pediatric orthopedics, spinal deformity and joint preservation to the practice. Since completing his studies, Dr. Feldman has been at the forefront of both simple and complex pediatric orthopedic treatments. He has helped many children with orthopedic deformities and conditions avoid surgery through early detection. His expertise with advanced non-surgical and surgical techniques has allowed hundreds of children to resume their normal activities after recovery times that are shorter than those of other methods.

Session Topic: To Help Patients, Parents And Care Givers To Have The Information To Make Informed Decisions About Making A Thoughtful Life Plan For An Individual With Arthrogryposis
Session Description: The purpose of my talk is to help patients, parents and care givers to have the information to make informed decisions about making a thoughtful life plan for an individual with arthrogryposis. I will be discussing how to create reasonable goals and expectations when dealing with arthrogryposis. What is available, surgically and non-surgically, to aid function? What is the sacrifice? How can we achieve stronger muscles with more joint motion to achieve the outcomes we deem possible? At what age will we create these goals? Do we have to choose between standing and sitting? Would stem cells help?

Friday, July 3rd | 9:00 AM - 9:45 AM | Mobility | Location: Easton A

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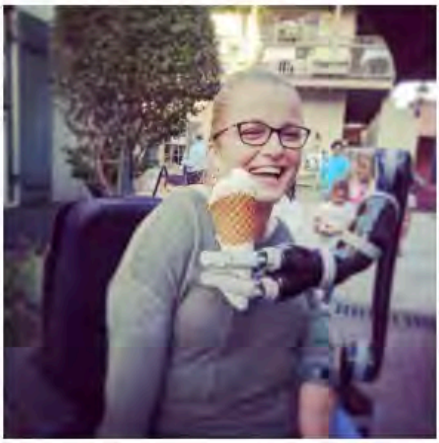
Bio: Mr. Bong Delrosario Currently serves as Director of Transportation Policy and Programs, for the Maryland Department of Disabilities. With an exceptional background dealing with statewide transportation issues concerning the disabled and older age communities. Experienced Recruiter with a demonstrated history of working in the health wellness industry. Strong advocate for people with disabilities. Well skilled in cross disabilities. Skilled in Policy Change, Strategic Public Relations Planning, Customer Service, Data Entry, Staff Recruitment, and IT Operations. Also serves as the Vice President of the "League of Extraordinary Gentlemen Society" (L.E.G.S.) a peer mentoring group. Prior to my current position as VP, I served as the President of the LEGS organization while also being involved in several other organizations including the Christopher Reeve Mentoring Program. I foresee a bright future for LEGS and the disability community with the assistance of a great network of team players taking the necessary actions required to be successful.

Session Topic: Beyond Labels
Session Description: This presentation offers an insightful look into my life journey, beginning in the third grade. I will highlight three different documentaries filmed at pivotal stages: one in elementary school, one spanning middle and high school, and a final one produced 29 years after the first. Alongside these films, I will share the personal trials and tribulations I have experienced throughout my life as a person with AMC.

Friday, July 3rd | 9:00 AM - 9:45 AM | AMC Lived Experience | Location: Eston B



PARTNERS IN MEDICINE

Hey AMCSIers – want to try the Jaco Robotic Arm?

Please visit our booth at the exhibit. And meet Jaco user Sarah Gaver to learn more!

SPEAKER SESSIONS

SCAN FOR THE MOST UP-TO-DATE SPEAKER SCHEDULE

Bio: Ms. Sarah Turgeon-Desilets, MScPT, CAS, is a pediatric physiotherapist, future PhD student, clinician, and academic educator at McGill University with over a decade of experience in neuromuscular and rare pediatric conditions. She specializes in the clinical care, assessment, and rehabilitation of children and youth living with spinal muscular atrophy (SMA) and Duchenne muscular dystrophy and serves as a clinical evaluator in multiple international rare disease trials. Sarah is actively involved in advancing rare disease care through research, education, and provincial leadership. Her work focuses on improving standardized assessment, building clinician capacity, and promoting evidence-based, patient-centered care for individuals living with rare neuromuscular disorders.

Bio: Ms. Liezel is the mother of a child with Arthrogryposis Multiplex Congenita (AMC), Liezel brings a lived experience perspective to the DARE Partnership (Developing Arthrogryposis Rehabilitation Expert Guidance, Dissemination through Partnership). Through their family's journey navigating healthcare, rehabilitation services, and advocacy, Liezel has gained valuable insight into the challenges and priorities faced by children with AMC and their families. Liezel has contributed to the co-design and review of educational resources and dissemination strategies to ensure they are meaningful, accessible, and relevant to families. Passionate about amplifying the voices of individuals with lived experiences and supporting the translation of evidence-based rehabilitation recommendations into practical resources that can improve outcomes and empower families across Canada.

Session Topic: From Collaboration to Impact: Developing E-Learning for Rare Neuromuscular Diseases
Session Description: Rare neuromuscular diseases present unique challenges for education and knowledge sharing among healthcare professionals, patients, families, and community partners. This presentation will highlight the importance and opportunity of co-developing meaningful educational resources through collaborative partnerships that include clinicians, researchers, patient advocates, and individuals with lived experience. We will describe the development process of an e-learning program for arthrogryposis, designed to improve access to reliable, practical, and patient-centered information. We will discuss key steps in the creation of the modules, including needs assessment, stakeholder engagement, content co-design, and adaptation for diverse audiences. Finally, we will explore the impact and broader implications of collaborative e-learning initiatives in rare diseases, including increased accessibility to knowledge, empowerment of patients and families, and opportunities to strengthen interdisciplinary care and international collaboration.

Friday, July 3rd | 10:00 AM - 10:45 AM | Research | Location: Easton A

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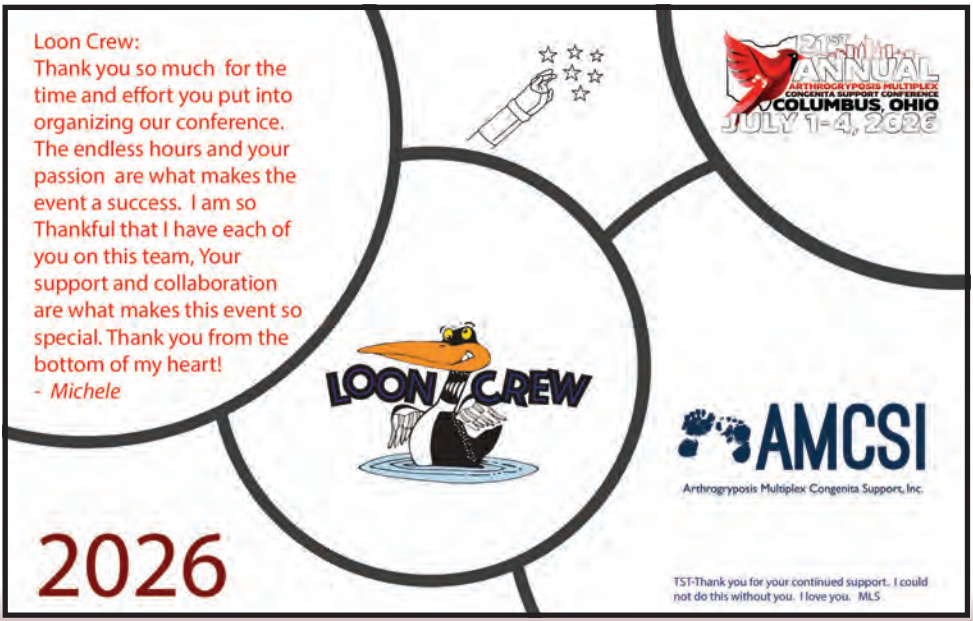
Bio: Ms. Jan Shea, MSW, joined Virginia Commonwealth University's Center on Transition Innovations (CTI) in 2014, bringing a rich background in juvenile justice and mental health. As the program coordinator for the recently accredited ACE-IT in College program, Jan fosters a sense of belonging and community for young adults with intellectual disability pursuing inclusive higher education at Virginia Commonwealth University. Over the past decade, she has contributed to various CTI projects, including providing mental health support to transfer students and coordinating employment for women with traumatic brain injuries (TBI) and spinal cord injuries (SCI). Outside of work, Jan enjoys paddleboarding around Greater Richmond, spending time with her family, and pursuing her doctorate in Educational Leadership.

Bio: Mr. Jake Gates-Ehlers is co-appearing with Jan in their session titled 'Let's talk about college and education pathways after high school.'

Session Topic: Let's Talk About College And Education Pathways After High School

Session Description: Be it a 2 or 4-year college, technical schools, or workforce programs – there are lots of choices and it can feel like a lot. Join Jake Gates-Ehlers and Jan Shea to learn about that transition out of high school. This informal presentation will go over some of those key differences between high school and college, discuss college accomodations, and create space to brainstorm that college search process. We want to help answer questions or give some tips about navigating some of those systems.

Friday, July 3rd | 10:00 AM - 10:45 AM | College Transition| Location: Easton B



SPEAKER SESSIONS

SCAN FOR THE MOST UP-TO-DATE SPEAKER SCHEDULE

Bio: Dr. Maureen (Reenee) Donohoe, PT, DPT Emeritus, is a board-certified pediatric clinical specialist with over 36 years of expertise in pediatric orthopedics, specializing in contracture disorders, clubfeet, and brittle bone diseases. She recently retired from clinical practice at Nemours Children's Health in Wilmington, Delaware, where her career included 20 years of part-time work in educational physical therapy. Currently, Dr. Donohoe remains active in clinical research with both Nemours and the University of Delaware physical therapy research lab. She also practices per diem at a private, physical therapist-owned clinic, focusing on adult care and aquatic exercise. A leading expert in her field, she is a contributing author on 21 text book chapters including Arthrogryposis Multiplex Congenita in all seven editions of Physical Therapy for Children. She has been involved in over 20 published research papers related to issues around AMC. In her free time, she volunteers with an adaptive rowing program.

Session Topic: The Top 10: Things A PT Might Share That May Surprise You
Session Description: This session will address key aspects across the early years and into adulthood as it relates to therapy and function.

Bio: Dr. Matthew Dobbs, MD, FACS is director of the Dobbs Clubfoot Center at the Paley Institute in West Palm Beach, Florida. Prior to that he was the Dr. Asa C. and Mrs. Dorothy W. Jones Professor of Orthopedic Surgery and the Director of Strategic Planning at Washington University School of Medicine. Dr. Dobbs trained under Ignacio Ponseti MD *(Ponseti, method)*. Since that time, he has introduced the Ponseti method for clubfoot management to surgeons in more than 50 countries. Dr. Dobbs is dedicated to Research and Teaching. He co-directed an NIH funded musculoskeletal genetics research laboratory and was founder (2001) and director of the clubfoot clinic at Saint Louis Children's from 2001-2020. He has been named a top orthopedic surgeon by US News & World Report, Top Doctors, Castle Connelly, Consumers' Research Council, Orthopedics This Week, the International Association of Orthopedic Surgeons, and St. Louis Magazine. He has been featured in the Chicago Tribune, San Francisco Chronicle, and the LA Times. He is internationally recognized for his expertise and innovation in the field of pediatric foot and lower limb deformities and experience with the differences that can arise with Arthrogryposis, Spina Bifida, Nail Patella Syndrome, and genetic conditions. He is the founder of the Dobbs method for treatment of vertical talus and remains the leading innovator in bracing for foot deformities. He values the multidisciplinary efforts needed to help children be their best self and minimize recurrences.

Session Topic: Atypical Clubfoot And Foot Deformities In Arthrogryposis
Session Description: Arthrogryposis is associated with various foot deformities requiring specialized treatment expertise. In this session, I will discuss clubfoot subsets and their treatment. We will discuss other foot conditions such as vertical talus and progressive foot deformities associated with Arthrogryposis.

Friday, July 3rd | 11:00 AM - 11:45 AM | Uppers | Location: Easton B

Dr. Harold J. P. van Bosse is proud to celebrate his 20th anniversary as a member of AMCSI!

As a strong advocate for his patients, Dr. van Bosse is honored to work with AMCSI to achieve a more fulfilling world for everyone with AMC and their families. Now practicing at Good Samaritan University Hospital in West Islip, Long Island, New York, Dr. van Bosse continues to work with his patients to help them reach their fullest potential by addressing their orthopedic needs and helping them adapt their abilities to take on the world in ways that bring them the most satisfaction.

Learn more about Dr. van Bosse at www.HvanBosseMD.com, or to make an appointment contact his office at (631) 228-5525

Bio: Dr. Harold J. P. van Bosse has been practicing pediatric surgery exclusively since completing his orthopedic residency at the University of Illinois in Chicago in 1994, and his fellowship at Toronto's Hospital for Sick Children in 1995. His specialty interests within pediatric orthopedics are arthrogryposis multiplex congenita (AMC), Prader-Willi syndrome (PWS), idiopathic clubfoot deformity, limb malalignment conditions, and pediatric spine deformities, especially of the growing spine. AMC and PWS alone make up more than 90% of his practice, allowing him to delve deeply into his special interest. He has published widely on topics related to arthrogryposis, clubfeet, and Prader-Willi syndrome. When developing an arthrogryposis center, the goals are to allow children with arthrogryposis to reach their fullest potential by addressing their limb deformities and helping them function/adapt to their limitations. Dr. van Bosse considers himself privileged to follow patients from North and South America, Europe and Asia. He is excited to announce that he has joined Good Samaritan Hospital in West Islip, NY, part of the Catholic Health Services. He could not have gotten this far without the support of his wife, Ana.

Session Topic: A Discussion Designed To Provide A Structure To Understand Arthrogryposis
Session Description: Arthrogryposis multiplex congenita is a term to describe a spectrum of disorders that all have in common babies born with multiple joint contractures. This talk is an overview, designed to provide a structure to understand arthrogryposis, the conditions that cause it, and the differences between diagnoses. There will be special focus on treatment of foot deformities (clubfoot and congenital vertical talus), hip deformities (contractures and congenitally dislocated hips), and knee contractures (both flexion and extension). Scoliosis will also be discussed, with an emphasis on different forms of treatment.

Friday, July 3rd | 2:00 PM - 2:45 PM | Understanding Arthrogryposis | Location: Easton B

Bio: Misha Walker is an international disability advocate, speaker, writer, and founder of The Dream Walker Project. Born with Arthrogryposis Multiplex Congenita (AMC), she has spent almost a decade traveling the world, connecting with individuals and families affected by AMC, and helping raise awareness through storytelling, community building, and advocacy. Through The Long Road to AMC Awareness, an annual road trip initiative, Misha and her husband Michael have visited hundreds of families across multiple countries, reminding people that they are not alone. Known for her authenticity, vulnerability, and heartfelt approach, Misha encourages others to embrace who they are, live boldly, and discover the power that comes from showing up as their true selves.

Session topic: The Power Of Authenticity
Session Description: At a world that often pressures disabled people to shrink, soften, or perform acceptability, authenticity can become an act of freedom. In this talk, AMCSI ambassador and Dream Walker Project founder Misha Walker shares how embracing her full, unapologetic self transformed not only her confidence, but the way she moves through the world. Through personal stories, vulnerability, humor, and hard-earned perspective, this session explores the power of showing up truthfully in a body that society constantly tries to define for you. Attendees will leave with a deeper understanding of how authenticity can create connection, self-worth, visibility, and unexpected opportunities. More than anything, this talk is an invitation to stop hiding and start living fully as exactly who you are.

Friday, July 3rd | 3:00 PM - 3:45 PM | Power Of Authenticity | Location: Easton A & B

CONFERENCE HIGHLIGHTS

Jammin' with Julie in Columbus!

Board Certified Music Therapist Julie Melton, based in Charlotte, NC, brings experience across hospital, school, & community settings. A 2023 Queens University of Charlotte graduate, she sings and plays guitar, ukulele, & piano, & is passionate about inclusive, accessible spaces for all abilities.

Musicians of all levels are invited to join the jam at the 21st Annual AMCSI Conference.

Friday, July 3rd | 2:00 PM - 2:45 PM
Location: Easton A

We're excited to have Aly & Navina as the official Pre-Teen & Teen Moderators!

Aly is passionate about disability awareness, acceptance, and accessibility for all. Aly volunteers at Scottish Rite Hospital with kids of various upper-limb differences & she is pursuing a degree in Speech-Language Pathology.

Navina has participated in multiple adaptive/disability programs, including adaptive skiing/snowboarding, & has served as an ambassador for Easterseals.

(See pg. 24 for the Pre-Teen & Teen schedule)

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To learn more about Shriners Children's arthrogryposis care, visit shrinerschildrens.org or call 800-237-5055.

Shriners Children's™

CONFERENCE MAP

Conference Hours

Wednesday, July 1st
4:00 pm - 10:00 pm

Thursday, July 2nd
8:00 am - 8:00 pm

Friday, July 3rd
8:00 am - 9:00 pm

Saturday, July 4th
9:00 am - 1:00 pm

AMCSI
Arthrogryposis Multiplex Congenita Support, Inc.

21st Annual
Arthrogryposis Multiplex Congenita Support Inc. Conference
July 1 - 4, 2026

SCAN FOR THE FULL CONFERENCE SCHEDULE

CONFERENCE MAP

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Wednesday, July 1st
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SCAN FOR THE FULL CONFERENCE SCHEDULE

FULL SCHEDULE

SCAN FOR THE MOST UP-TO-DATE CONFERENCE SCHEDULE

WEDNESDAY, JULY 1, 2026

2:30 PM - 3:30 PM | Volunteers Meetup ..... Easton Foyer

4:00 PM - 6:45 PM | Registration/Tshirt Pickup | AMC Store | Vendors | Silent Auction ..... Easton Foyer *(Silent Auction - Regent 3)*

7:30 PM - 8:15 PM | First-Time Attendees Welcome ..... Easton C, D, E

8:15 PM - 9:00 PM | Preteen/Teen Meetup ..... Hotel Foyer

7:30 PM - 10:00 PM | Informal Social Time For All Attendees Hotel Hotel Lobby/Bar(*Food & drink on your own)*

THURSDAY, JULY 2, 2026

8:00 AM - 6:00 PM | Registration/Tshirt Pickup | AMC Store | Vendors | Silent Auction ..... Easton Foyer *(Silent Auction - Regent 3)*

10:00 AM - 10:45 AM | Opening Ceremony - Keynote Speaker: Todd CraigheadEaston A & B

11:15 AM - 12:00 PM | Dr. Philip F. Giampietro ..... Easton A

11:15 AM - 12:00 PM | Adaptive Sports - Kimberly Kolstad ..... Easton B

11:15 AM - 12:00 PM | Teen Girls With AMC ..... Easton C

11:15 AM - 12:00 PM | Teen Boys With AMC ..... Easton D

12:00 PM - 2:00 PM | Lunch ..... *(On your own)*

2:00 PM - 2:45 PM | Dr. Lauren Hyer ..... Easton A

2:00 PM - 2:45 PM | Driver Rehabilitation Center For Excellence ..... Easton B

2:00 PM - 2:45 PM | Preteen Girls With AMC ..... Easton C

2:00 PM - 2:45 PM | Dads ..... Easton D

3:00 PM - 3:45 PM | Dr. Lisa V. Wagner ..... Easton A

3:00 PM - 3:45 PM | Dr. Harold J. P. Van Bosse ..... Easton B

3:00 PM - 3:45 PM | Moms Of AMCers (10 Under) ..... Easton C

3:00 PM - 3:45 PM | Adults With AMC Co-Ed ..... Easton D

4:00 PM - 4:45 PM | Dr. Kaveh Asadi-Moghaddam ..... Easton A

4:00 PM - 4:45 PM | Dr. Fran Guardo ..... Easton B

4:00 PM - 4:45 PM | Moms Of AMCers (Ages 11-17) ..... Easton C

4:00 PM - 4:45 PM | Preteen Boys With AMC ..... Easton D

6:45 PM - 8:00 PM | Dinner ..... Easton A-E

Schedule continued on Pg. 20

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FULL SCHEDULE

SCAN FOR THE MOST UP-TO-DATE CONFERENCE SCHEDULE

FRIDAY, JULY 3, 2026

8:00 AM - 5:00 PM | Registration/Tshirt Pickup | AMC Store | Vendors | Silent Auction ..... Easton Foyer *(Silent Auction - Regent 3)*

9:00 AM - 9:45 AM | Dr. David Feldman ..... Easton A

9:00 AM - 9:45 AM | Mr. Bong Delrosario ..... Easton B

9:00 AM - 9:45 AM | Men With AMC ..... Easton C

9:00 AM - 9:45 AM | Women With AMC ..... Easton D

10:00 AM -10:45 AM | Dr. Noémi Dahan-Oliel's Team - Ms. Liezel & Ms. Sarah ..... Easton A

10:00 AM - 10:45 AM | Ms. Jan Shea & Mr.Jake Gates-Ehlers ..... Easton B

10:00 AM - 10:45 AM | Men With AMC (Continued) ..... Easton C

10:00 AM - 10:45 AM | Women With AMC (Continued) ..... Easton D

11:00 AM - 11:45 AM | Dr. Maureen Donohoe ..... Easton A

11:00 AM - 11:45 AM | Dr. Matthew Dobbs ..... Easton B

11:00 AM - 11:45 AM | Adults With AMC Dating ..... Easton C

11:00 AM - 11:45 AM | Grandparents Of AMCers ..... Easton D

12:00 PM - 2:00 PM | Lunch ..... (On your own)

2:00 PM - 2:45 PM | Julie Melton ..... Easton A

2:00 PM - 2:45 PM | Dr. Reid Nichols ..... Easton B

2:00 PM - 2:45 PM | Moms Of Kids With Multiple Disabilities ..... Easton C

2:00 PM - 2:45 PM | Young Adults With AMC (Ages 18-30) ..... Easton D

3:00 PM - 3:45 PM | Misha Walker ..... Easton A & B

2:00 PM - 2:45 PM | Adults With AMC Dating ..... Easton C

7:00 PM - 9:00 PM | AMCSI Prom

9:00 PM - 11:00 PM | Set Up For Painting With Theresa ..... Regency 1 & 2

SATURDAY, JULY 4, 2026

9:00 AM - 12:00 PM | AMC Shop ..... Easton Foyer

9:00 AM - 12:00 PM | Silent Auction ..... Regency 3 *(All bidding ends at Noon)*

9:00 AM - 10:00 AM - 10:45 AM | AMCSI Group Photo ..... Easton A-E

11:00 AM - 12:00 PM | Painting With Theresa ..... Regency 1 & 2

12:35 PM - 1:00 PM | Closing Ceremony ..... Easton A & B

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PRE-TEEN & TEEN ACTIVITIES AND CHILDREN'S SCHEDULE

SCAN FOR THE MOST UP-TO-DATE CONFERENCE SCHEDULE

PRE-TEN & TEEN GROUP ACTIVITIES

WEDNESDAY, JULY 1, 2026

7:30 PM - 8:15 PM - First Time Attendees Welcome ..... Easton C, D, & E

8:15 PM - 9:00 PM - Pre Teen/Teen Meetup ..... Hotel Foyer

THURSDAY, JULY 2, 2026

11:15 AM - 12:00 PM - Teen Girls ..... Easton C

2:00 PM - 2:45 PM - Pre Teen Girls ..... Easton C

5:00 PM - 6:00 PM - Teen Pool Social ..... Hotel Pool

FRIDAY, JULY 3, 2026

1:00 PM - 1:45 PM - Ice Cream With Pre Teens ..... Meet in Lobby *(Graeter's Ice Cream)*

CHILDREN'S PROGRAMMING IN HONOR OF BRIAN WAYNE PAGE

THURSDAY, JULY 2, 2026

2:00 PM | Make-It Take It Part 1 ..... Regent 1 & 2

3:00 PM | Make-It Take It Part 2 ..... Regent 1 & 2

FRIDAY, JULY 3, 2026

9:00 AM | Story Time With Tammy ..... Regent 1 & 2

10:00 AM | Escape Room! ..... Regent 1 & 2

11:00 AM | Music Therapy With Julie ..... Regent 1 & 2

2:00 AM - 4:00 PM | Game Time With Your Favorite Doctors And Therapists ..... Regent 1 & 2

>>DISCLAIMER: PARENTS MUST STAY WITH THEIR CHILDREN IN CHILDREN'S PROGRAMMING.<<

CHILDREN'S PROGRAMMING & REMINDERS

ALL children under the age of 18 MUST be supervised by an adult at ALL times. Due to the lack of volunteers, we are unable to provide childcare.

Kids must have an adult (ages 16 or up) with them at all times, including children's programming.

An individual aged 14 or older MUST remain in the Children's Programming Room with your child(ren) during all Children's Programming.

During Painting with Theresa please don't let children 'swim' in the paint.

Badges MUST be worn to all conference sessions, including prom, and activities. AMCSI reserves the right to deny entrance to conference events to individuals lacking conference ID badges. This is for the safety and security of all Attendees. You may be asked to return to your guestroom to get your badge. PLEASE wear them at all times in the conference area.

Children's Programming is available during conference sessions but is not childcare.
Please use the hashtag #AMCOH26 when posting to social media!

The hotel elevators are for the use of all guests, children are not permitted to "play" on the elevators.

In being respectful of our presenters, individual conversations should be taken outside of the conference rooms during presentations.

Areas outside of the conference rooms are available should your child need your full attention while a speaker is presenting.

Please remember we are able to provide this conference through the generosity of our members and attendees.

Alcohol is NOT permitted at any AMCSI event. Please visit one of the many establishments on the hotel property.

Attendees may not use the conference space after scheduled events have ended for the day.

As always, consult with your or your child's physician before implementing any new ideas as a result of attending this conference.

Please remember that aside from your hotel room, all hotel areas are considered "Public Spaces" and individuals who are not a part of our conference may pass through. Please keep all belongings you bring to the meeting space with you at all times and be aware of those around you
.
All Attendees agreed to abide by the code of conduct at registration. AMSCI reserves the right to enforce the code of conduct.

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Thank You To Our Exhibitors

(Some of the Exhibitors are also Sponors)

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BOARD OF DIRECTORS

ALEXIS RECORD
President

Alexis Record lives in San Diego with her spouse, Charles, their adult daughter with AMC, Laelia, their teenager with AMC, Felix, as well as their four kitties, the leopard gecko, a one-eyed ball python, a random number of dubia roaches at any given time, and way too many brine shrimp. When not enjoying the chaos at home, Alexis serves as the executive director of Sunday Assembly San Diego, a non-religious, inclusive community that does service projects in their surrounding neighborhoods. In 2014, she wrote a children's book called Different Like Me to help kids understand arthrogryposis and be able to pronounce it. It features both her children in cartoon form.

MATTHEW P. CAVEDON
Vice President

Matthew P. Cavedon has arthrogryposis and uses a wheelchair. In his youth, Cavedon was a national spokesperson for Boundless Playgrounds and a member of the National Council on Disability's Youth Advisory Committee. He graduated from Harvard College and Emory University. A former law clerk and public defender, he is currently the Robert Pool Fellow at the Center for the Study of Law and Religion at Emory University. Cavedon and his wife live in South Carolina and are active in their Catholic parish.

MICHELE SCHAFFER
Vice President of Programming

Michele Schaffer and her husband Allen have four adult children, David, Andrew-AMC, Christopher, and Kaytlin. Michele currently works for the New Albany Plain Local School District as an Intervention Specialist. She joined the Board of Directors of Arthrogryposis Multiplex Congenita Support, Inc., in 2006. With the help of the amazing Loon Crew, she has planned the Annual Conference since 2010. In her free time, Michele enjoys reading, crafting, and volunteering. Michele and her family currently reside in Columbus, Ohio

BOARD OF DIRECTORS

Dr. Harold J. P. van Bosse - *Medical Director*

Dr. Harold van Bosse has been practicing pediatric surgery exclusively since completing his orthopedic residency at the University of Illinois in Chicago in 1994, and his fellowship at Toronto's Hospital for Sick Children in 1995. His specialty interests within pediatric orthopedics are arthrogryposis multiplex congenita (AMC), Prader-Willi syndrome (PWS), idiopathic clubfoot deformity, limb malalignment conditions, and pediatric spine deformities, especially of the growing spine. AMC and PWS alone make up more than 90% of his practice, allowing him to delve deeply into his special interest. He has published widely on topics related to arthrogryposis, clubfeet, and Prader-Willi syndrome. When developing an arthrogryposis center, the goals are to allow children with arthrogryposis to reach their fullest potential by addressing their limb deformities and helping them function/adapt to their limitations. Dr. van Bosse considers himself privileged to follow patients from North and South America, Europe and Asia. He is excited to announce that he has joined Good Samaritan Hospital in West Islip, NY, part of the Catholic Health Services. He could not have gotten this far without the support of his wife, Ana.

JOSHUA RUSSELL - *Treasurer*

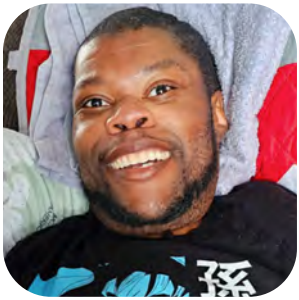
Joshua Russell and his wife Ashlee are originally from Topeka, Kansas, and moved to Florence, Alabama, in late December 2015. They have one daughter, Piper, who was born in 2017. Shortly after Piper was born she was diagnosed with AMC (Amyoplasia). They connected with AMCSI through Facebook and attended their first conference that year in Columbus. The AMCSI community and conference was instrumental in getting them connected with knowledgeable healthcare teams and other families. Outside of AMCSI Josh is a Partner at Patterson, Prince & Associates, PC and has experience in private, investment, and public (including not-for-profit) accounting.

ERIN MILLER - *Secretary*

Erin was born with AMC. Growing up in a small town, Erin quickly learned how to adapt to her surroundings and find creative ways to do things, like rearranging her bedroom back to how she wanted it while her mother was sleeping one night! She has her Masters in Rehabilitation Counseling and a bachelor's degree in Criminal Justice. Erin lives with her four dogs and four cats in Harrisburg, Pennsylvania, and works full-time for the Social Security Administration. She is passionate about equality and working to improve the lives and independence of people with disabilities. In her free time, Erin enjoys playing with her dogs and spending time with friends and family.

BOARD OF DIRECTORS

MARK INDREIKA - *Parliamentarian*
Mark Indreika has spent 29 years teaching high school English in the Chicago area. He attended Northern Illinois University earning undergraduate degrees in journalism and in English education. He also completed a graduate degree in English and American Literature. Before the pandemic, he spent two years editing and writing the old AMCSI newsletter, AMC Today. He enjoyed the work since he has a passion for telling stories, especially the stories of people with AMC. When he retires from teaching in 2026, he looks forward to devoting even more time to AMCSI. He said this about the organization, "My wife Jane and I have been members of AMCSI for over 10 years. Before my first conference, I saw myself as somewhat of an anomaly, but now I see myself as a member of a very large and inclusive community. People with AMC come from all socioeconomic backgrounds; from all cultures and races; and from all political and spiritual persuasions. Unlike the rest of our divided society, however, our community has found unity.



LORENZO HARRISON - *Member-At-Large*
My name is Lorenzo Harrison, but all of you know me as either Rod or Uncle Rod. I was born with Arthrogryposis Multiplex Congenita, where I am affected in all four limbs of my body. Gaming, technology, AMC, sports, and family are all things that will bring me to the table. I have always wanted to be an activist for AMC. I have a deep passion for always wanting to help others in any way that I can. I want to leave the world a little bit better than when it was before I got here. Professionally speaking, I am a technical project manager/ producer within the world's gaming, IT, and entertainment sectors. I have over 11 years combined, either developing, leading, or producing content for the masses. When I am not helping others in my spare time, you can find me playing games on my PlayStation, Xbox, or laptop. I am incredibly honored to be a board member, and I promise to put the family first in every decision I make. I thoroughly look forward to serving all of you to the best of my abilities and having a little fun in the process.

SIERA LEONE - *Member-At-Large*
Siera discovered AMCSI while searching for resources on Arthrogryposis and found a supportive community. She works for RIPIN, a nonprofit that helps all Rhode Islanders throughout their lifespans navigate the special education, health insurance, and healthcare systems. She supports RIPIN's administrative department, co-facilitates the Chronic Pain Self-Management Program, and is a mentor for the Youth Advisory Council, a group of youth and young adults who make a difference in health issues affecting that population. Siera served on Rhode Island's Independent Living Council. She lives in Wakefield, Rhode Island. When not working, Siera enjoys good food, new experiences, and learning fun facts about the Ocean State.

BOARD OF DIRECTORS

TRACEY SCHALK - *Member-At-Large*

Tracey Schalk lives with AMC in all limbs. She has a bachelor's degree in Political science and disability studies from The Ohio State University. She has worked in various positions in Ohio's developmental disabilities system of care, doing case management and vocational rehab, and, currently, quality assurance and eligibility determination. She is on the Board of Directors for Arthrogryposis Ohio and was part of the team that helped start the AMC Adult Registry. She lives in Findlay, Ohio, with her husband, John, and dog, Winston.

MEDICAL ADVISORY BOARD

DR. HAROLD VAN BOSSE - *Medical Director*

Harold J.P. Van Bosse, M.D. has been practicing pediatric orthopedic surgery exclusively since completing his orthopedic residency at the University of Illinois in Chicago in 1994, and his fellowship at Toronto's Hospital for Sick Children in 1995. His specialty interests within pediatric orthopedics are arthrogryposis multiplex congenita (AMC), Prader-Willi syndrome (PWS), idiopathic clubfoot deformity, limb malalignment conditions, and pediatric spine deformities, especially of the growing spine. AMC and PWS alone make up more than 90% of his practice, allowing him to delve deeply into his special interest. He has published widely on topics related to arthrogryposis, clubfeet, and Prader-Willi syndrome. When developing an arthrogryposis center, the goals are to allow children with arthrogryposis to reach their fullest potential, both by addressing their limb deformities, as well as helping them to function/adapt to the limitations they have. Dr. Van Bosse considers himself privileged to follow patients from both North and South America, as well as Europe and Asia. He could not have gotten this far without the support of his wife, Ana.

DR. JUDITH HALL - *Medical Advisor*

Dr. Judith Hall is a clinical geneticist and pediatrician. She trained at Wellesley College, the University of Washington School of Medicine, and the Johns Hopkins Hospital. She is presently Emerita Professor of Pediatrics and Medical Genetics at the University of British Columbia, Vancouver, Canada. Her area of research interest is human congenital anomalies and in particular arthrogryposis (multiple congenital contractures). She has published over 300 original peer reviewed articles, 140 chapters, conference proceedings, and 10 books. Dr. Hall is also the co-author of the AMC Text Atlas . She has been involved in arthrogryposis clinics for over 35 years with a particular interest in sorting out the causes (including genetic), natural history, and best therapies for individuals affected with arthrogryposis. She has published over 50 articles and chapters on arthrogryposis, and she continues to be actively involved in learning as much as possible about arthrogryposis so that she can help families and affected individuals.

DR. MAUREEN DONOHOE PT, DPT - *Medical Advisor*
Dr. Maureen Donohoe is a board-certified pediatric clinical specialist specializing in pediatric orthopedics. She has worked with contracture disorders for over 30 years as the primary physical therapist in the hospital's Arthrogryposis Program, Osteogenesis Imperfecta Program, and Clubfoot Program. Dr. Donohoe authored the chapters on arthrogryposis and osteogenesis imperfecta in all six editions of Physical Therapy for Children, authored Therapy, Orthotics and Assistive Devices for Osteogenesis Imperfecta in Osteogenesis Imperfecta: A Case-Based Guide to Surgical Decision-Making and Care, Ambulatory Assistive Devices for Children and Youth with Cerebral Palsy and Activities of Daily Living Supports for Persons with Cerebral Palsy in Cerebral Palsy 2nd edition, the Relapsed Clubfoot in Paediatric Clinical Case Studies, as well as Sports and Recreation in Children with Osteogenesis Imperfecta: Strategies to Enhance Performance. She has been involved in over ten research studies on the physical ability of individuals with arthrogryposis and club feet. She has lectured nationally and internationally on these topics. This is her 15th visit to share information at the AMCSI meeting.

DR. SARA LEMIN - *Medical Advisor*
Dr. Sara Lemin is a board-certified Obstetrician Gynecologist practicing full-time in Canton, Ohio. She has served as the chairman of the Department of OB/GYN at Cleveland Clinic Mercy Hospital and is currently an Assistant Program Director of the OB/GYN residency program at Aultman Hospital/ NEOMED. In addition to her private practice, Dr Lemin has a particular interest in the prenatal detection of arthrogryposis and raising awareness among pregnancy care providers in order to help more families prepare for the birth of their child with AMC. Dr Lemin and her husband Ian have seven children, including two boys with AMC, blessing them with a unique position at the intersection of AMC and pregnancy care. Together they founded the non-profit Take TIME For AMC, an organization dedicated to research and promotion of the prenatal detection of arthrogryposis. Dr Lemin is honored to work alongside her distinguished colleagues on the Medical Advisory Board for AMCSI.

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AMCSI INTERNATIONAL AMBASSADOR

MISHA "DREAM" WALKER
International Ambassador

Misha Walker is an international disability advocate, speaker, writer, and founder of The Dream Walker Project. Born with Arthrogryposis Multiplex Congenita (AMC), she has spent almost a decade traveling the world, connecting with individuals and families affected by AMC, and helping raise awareness through storytelling, community building, and advocacy. Through The Long Road to AMC Awareness, an annual road trip initiative, Misha and her husband Michael have visited hundreds of families across multiple countries, reminding people that they are not alone. Known for her authenticity, vulnerability, and heartfelt approach, Misha encourages others to embrace who they are, live boldly, and discover the power that comes from showing up as their true selves.

CONFERENCE PLANNING COMMITTEE

MICHELE SCHAFFER

BETSY GATES-EHLERS

MAUREEN GOEDE

ANA VAN BOSSE

JAN SHEA

LARINA SWANSON-CARTER

BETH SELLERS

ANI SAMARGIAN
AMCSI Founder/Community Support Advocate

Ani's AMC journey began 23 years ago when her daughter was diagnosed in utero. Faced with fear and little guidance, Ani channeled her experience into building an organization that now shines a light for thousands worldwide. Through partnerships with leading experts, Ani has helped shape rehabilitation recommendations and amplify the voices of those living with arthrogryposis.

Ani continues to collaborate with top international researchers and healthcare professionals to advance the understanding of AMC and improve patient care through the International Consortium for Arthrogryposis. Ani is excited to continue collaborating with other leaders of international patient support groups, a collaboration that was developed at the 4th International Symposium on Arthrogryposis in Montreal.

A passionate advocate for awareness, research, and innovation in the AMC community, Ani works tirelessly to improve the quality of life for all those impacted by this condition. She also leads outreach, support, and fundraising initiatives with AMCSI to promote inclusion, acceptance, and support for the AMC community.

TED HOUSER
I. C. - Director of Sales/Marketing & Digital Strategy

Ted Houser is a seasoned artist and creative professional with over 20+ years of experience in graphic design, event production, marketing, and web development. As the founder and owner of TBSDesigns since 2006, he has collaborated with businesses and organizations around the world, specializing in branding, website creation, and international logo designs. Based in Philadelphia, Ted is proud to bring his expertise and lived experience as an individual with Arthrogryposis Multiplex Congenita (AMC) to the team, dedicated to supporting and empowering the AMC community and their families.

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Thank you Misha & Mike!

AMC AWARENESS

Follow The Dream Walker Project on Facebook at:
https://www.facebook.com/mishadreamwalker

AMCSI

Arthrogryposis Multiplex Congenita Support, Inc.

Becoming a member of Arthrogryposis Multiplex Congenita Support, Inc. is about supporting an organization that truly values the importance of (AMC) information, resources, research & awareness #freely & continuing to do so.

Become a vested member in AMCSI & enjoy the following benefits:

- Discount on registration fees to the AMCSI yearly conference
- Access to AMCSI's annual public meetings and monthly BOD meeting minutes
- Voting rights
- Ability to apply to serve for a vacant spot on AMCSI Board of Directors
- Ability to participate in various volunteer and board committees
- Ability to participate in member spotlights in seasonal AMCSI newsletters
- Ability to apply for grants Mini Meetup, Research, Bereavement, College Scholarship
- AMCSI membership also provides early-bird conference registration at a discounted rate

AMCSI's annual membership is valid for one year from the time of purchase. Auto-renew is optional if selected at checkout. Please note that auto-renewal will be deactivated upon request or at the discretion of the AMCSI Board of Directors. Membership must be active before applying to any grant.

Supporting AMCSI through membership helps guarantee that.
https://amcsupport.org/become-a-member/

@AMCSUPPORT

With Deepest Gratitude to Our Fundraisers

To every individual, family & team who has fund raised on behalf of AMCSI, **THANK YOU.**

Your dedication, compassion & tireless support make it possible for us to uplift and empower the AMC community in meaningful ways. Because of your efforts, we're able to provide:

- **AMCSI Conference Scholarships**
- **Accessibility, Adoption, Bereavement, Medical Travel, Mini-Meetup & Research Grants**
- **And the unforgettable AMC Holiday Gran**t, bringing joy & lasting memories to families during the holidays.

They say it takes a village & your commitment proves that, year after year. Every story shared, every scholarship granted & every moment celebrated at our Annual Conference is made possible because of you.

Thank you for believing in the mission & helping us make a difference.

And we're here to support you too!

AMCSI can help amplify your fundraising with a dedicated landing page that includes your fundraising story, your logo (if you have one), and a custom donation setup where your supporters can donate directly to your cause. 100% of those funds go right back into helping families through all the programs and grants listed above.

To learn more about hoe you to can create your own fundraiser, please visit: **https://amcsupport.org/ways-to-help-amcsi/**

Thank you for being part of our village. Together, we can make a difference.

Scan to donate to AMCSI today, to help our cause!

venmo

Valerie's REMARKABLE STEPS

VALERIE PEPE

ILLUSTRATIONS BY FERNANDO QUINTERO

Theresa Lucas is a watercolor artist from Anderson, Indiana, born with Arthrogryposis Multiplex Congenita (AMC). She paints using a brush held in her mouth, a method that gives her greater freedom of expression. Her work has been exhibited in local galleries and at the Indiana State Fair.

Theresa serves as President of the Art Association of Madison County and coordinates the annual county-wide high school art exhibition. She previously served as Vice President and President of AMCSI (2006–2017) and has led the popular "Painting with Theresa" sessions at every AMCSI conference since 2006.

Her honors include being named a 2008 Hoosier Hero in the Arts and receiving WETV's "We Do Good—Women on Their Way" Award in 2010.

Theresa also advocates for disability awareness and frequently visits schools to share her story. She enjoys time with family and friends in her free time.

Painting with Theresa is on Saturday from 11:00 AM - 12:00 PM | Location Regancy 1 & 2

Thank you...

To Our Volunteers, Session Moderators, and Scholarship Donors

The 21st Annual AMCSI Conference would not be possible without the incredible generosity, time, and dedication from each and every one of you.

Your support makes a lasting impact.

Thank you for helping bring our community together.

Thank You, Bob Wellmon!

We're thrilled to have the talented photographer Bob Wellmon to capture the unforgettable moments of our 21st Annual AMCSI Conference!

Be sure to say hello to him & capture your favorite conference memory!

We can't wait to explore this year's photo library & share the joy, connection & energy you help preserve through your lens. Thank you, Bob, for your continued support & dedication!

Check out his photography at:
https://www.bobwellmon.com

AMC MEMORIAL

“A moment in our arms, a lifetime in our hearts.”

Having a loved one diagnosed with arthrogryposis is a journey filled with challenges, strength, and profound emotion. For some in our community, that journey has included the unimaginable heartbreak of loss.

Over the years, we’ve stood together—celebrating milestones, offering support during the hardest days, and grieving side by side.

Our hearts are with you.
We carry the memory of your AMCer with us always. Their light continues to shine through the love we share, the connections we build, and the enduring spirit of our AMC family.

Alannah Nicole Marshall
Alexis Irelyn Pendak
Andrea Nicole “Nickie” Dolan
Arthur Swales
August Edward Pierce
Barbara Waite
Brian Wayne Page
Caitlyn Rose Rout-Langdale
Caleb Michael Mayo
Ciaran Green
Claire Jane Cocklin
Cynthia Ann Sneddon
David Border
Diana
E’zra Nelson
Emma Jean Schmidt
Ethan Alexander Garza
Gabriella “Ella” Lee Tucker
Henry Dobrovits
Ian Boyd Hixson
Isabel Rose Sander
Jake Charles Cohen
Jameson McCormick
Jared J. Orner
Jeanne Bozenhard
Kali Pauline Heglmeier
Karrington Riley Reynolds
Kendale John McCormick
Kenna Neil Cook
Klara Handke
Lainey Marie Horning
Laughton Joseph
Leah Catherine Tamash
Lua March Souza
Lydia Joy Morris-Bloom
Lydia Peyton-Irene Shea
Marisa Rose Border
Matt Rangel
Maxwell Samuel Benvie Taylor
Mireille Alethia Griepentrog
Nicholas Casey Bunch Evans
Nicholas John Martin
Olivia Grace Wagner
Olivia Helen Mockeridge
Patty Clarke
Patrick William Martin
Paul John Eterno
Payton Leigh Biddy
Rain Maia
Raquell Nicole Reid
Rebeca A. Patton
Rylee Gene Mann
Sarah Rose Tricarico
Savannah Nicole Lehl
Steve Chambers
Zander Christian Young
Zaya Lynn Crofut
Zoë Margaret Jacobs


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Sarah's Story

How One Family Found the Right Care Team at AMCSI

When Sarah was diagnosed with arthrogryposis, it marked the beginning of a medical journey that would lead her family to AMCSI. It was there they met Dr. Reid Nichols, an orthopedic surgeon at Nemours Children's Hospital, Delaware. It would prove to be a life-changing encounter. "We knew right away that this is where we needed to be," says Sarah's mother, Kerstin.

As part of our whole child approach to care, Sarah is treated by Dr. Nichols, alongside a team of experts in orthopedics, neurology, gastroenterology, urology, therapy, and more. "It's so comforting to know that the doctors consider Sarah a child and not a number," explains Kerstin. "They talk across departments to make the best plan for her."

Her advice for parents facing a similar diagnosis is simple. "Don't settle for OK. Find a team that cares and has the knowledge to give you and your child the best."

Scan to learn more about our world-renowned Arthrogryposis Program.

NEMOURS CHILDREN'S HEALTH. | Nemours.org