

2025 OFFICIAL CONFERENCE PROGRAM

20th *Annual*
AMCSI
ARTHROGRYPOSIS MULTIPLEX CONGENITA SUPPORT INC.
JULY 9-12 | NORFOLK, VIRGINIA *Conference* 2025

Celebrating 20 years with our AMC family!

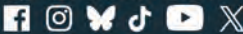


Arthrogryposis Multiplex Congenita Support, Inc.



AMCSUPPORT.ORG

@AMCSUPPORT



“Do what you can,
when you can,
with what you’ve got,
while you’ve got it”

Curt Moody

Williams Farm Recreation Center
Norfolk, Virginia

ASchaffer@moodynolan.com



Moody Nolan



LETTER FROM ALEXIS



Dear AMC Family,

Welcome to our 20th annual AMCSI Conference! I'm so happy you're here!

Our team is so excited to have you all and your various crews here for days of fun, connection, and just the right amount of organized chaos. Whether you're here for the workshops, the speakers, the children's programming, the chance to wear matching T-shirts (you know who you are), or just the big ol' family vibe, we're thrilled to have you!

This year is the big 2-0. If Conference were a person it would be old enough to drive, buy a boat, or join the National Guard. But not old enough to avoid being carded, so everyone WEAR

YOUR NAME TAGS! (*Just kidding, but seriously, wear them.*) You can't get into workshops or even prom without them. Our lawyer said something about blah blah liabilities mean no more conference blabitty blah. He looked stern, okay?

Our little group has grown from just a handful of families that very first conference to a national organization with international reach! Our group photo went from a selfie to needing a camera person to borrowing a drone!

Thanks for being part of this joyful gathering. Let's make some memories, share some laughs, and maybe learn a thing or two along the way. Our team is here to help make sure everything runs smoothly.

Let's get to it!

Alexis Record – *President* | AMCSI



LETTER FROM ANI



Dear AMC Family,

Welcome to the 20th Annual AMCSI Conference. What an incredible milestone to celebrate with each of you! Whether this is your first conference or your twentieth, I am so grateful you're here with us as we mark two decades of connection, growth, and unwavering hope.

Twenty years ago, AMCSI was born from a desire to ensure that no family facing a diagnosis of arthrogryposis would ever have to walk that journey alone. What started as a small network of parents and caregivers has grown into a vibrant, compassionate, and powerful community that continues to inspire me every single day.

This conference, and our progress as a community, would not be possible without the dedication of our medical partners. To the doctors, therapists, surgeons, researchers, and clinicians who devote your lives to understanding, treating, and advocating for individuals with AMC — thank you. Your work is not just advancing science; it is changing lives. We are especially grateful for the researchers passionately pursuing new insights into arthrogryposis and bringing hope to our families.

I would also be remiss if I didn't take a moment to honor the many board members, committee leaders, and volunteers—past and present—who have poured countless hours, days, and years into AMCSI. Your time, your energy, and your love have built the foundation we stand on today. You have helped shape a legacy that continues to grow, touch hearts, and empower families around the world.

And to our extraordinary Conference Committee, lovingly known as “the Loons” — there are truly no words big enough to capture my gratitude. For 20 years, you have given your heart, time, and love—with no pay, no spotlight, and no expectation other than to bring joy, comfort, and connection to our families. Year after year, you organize, plan, and execute this conference with care and devotion that shines through every detail. We simply could not do this without you. Thank you for being the soul behind the scenes and for making this gathering a reality year after year.

As we look ahead to the future of AMCSI, we carry with us 20 years of strength, stories, and support — and the unwavering belief that together, we can do anything.

Here's to celebrating all that we've accomplished, and to dreaming even bigger for the years to come.

With all my heart,

Ani Samargian – *Founder/Community Support Advocate*



LETTER FROM THE PLANNING COMMITTEE



Dear Friends,

The Conference Planning Team (AKA: The Loon Crew) would like to welcome you to the 20th Annual Arthrogryposis Multiplex Congenita Support, Inc. conference in beautiful Norfolk, Virginia! It is hard for some of us "Old Timers" to believe that we made it to celebrate 20 years! If you are a first time attendee, WELCOME! If you are a returning attendee, WELCOME BACK! We are glad you are here.

We would like to extend our thanks to all who have offered to volunteer. We could not offer the programming that we do without your help. Volunteers are what make this conference happen. We can plan, but without YOU we couldn't follow through. THANK YOU!

Over the next three days, you have the opportunity to participate in many different informational and support sessions. Please remember that all of our presenters volunteer their time and travel, and while we know you may wish to engage them in personal conversations; please understand that some of our speakers are on very tight timelines and may need to leave quickly to complete their travel.

We want the conference to be a comfortable experience for all, so do what is best for your family. If you need to take a break away from the activity, we understand! It can be overwhelming sometimes. So please feel free to attend the sessions that work best for your family's needs.

After the conference has ended, please look for an email from us. It will be sent to the email you used for registration. This email will contain a survey link. Please take a few moments and fill it out. Your feedback is important to us, and we use the information you provide to plan future conferences.

If you are interested in joining the Loon Crew, please reach out to one of the team! We're always looking for help!

Welcome to Norfolk!

The Loon Crew



Vice-President of Programming

Maureen Goede

Beth Sellers

Betsy Gates-Ehlers

Jan Shea

Larina Swanson-Carter

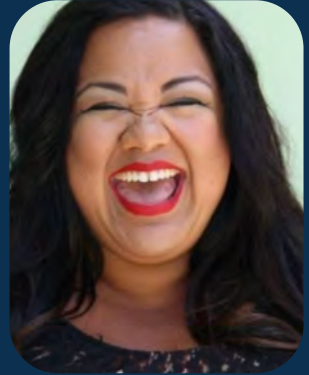


Ana Van Bosse

SPEAKER SESSIONS

KEYNOTE SPEAKER - Jennifer Kumiyama

Bio: Jennifer was born with Arthrogryposis and uses a wheelchair daily. She identifies as an Asian, Pacific Islander & Black woman with a disability. She serves as Citywide Accessibility Coordinator at the City of Long Beach – where she is tasked with making sure the City is in compliance with Title II of the Americans with Disabilities Act.



A disability activist for over two decades, her work began in 2002 when Jennifer was cast in Disney's "Aladdin: a Musical Spectacular" at Disney California Adventure Theme Park, where she was the first performer in a wheelchair to ever be on any Disney stage in the world. Jennifer used her performing platform at Disney to compete & win the title of Ms. Wheelchair California 2010 where she promoted empowerment for youth with disabilities, speaking throughout the state of California & the nation during her reign. Other credits include Carmen in 'The Sessions', MTV's 'awkward.', & 'Celebrity Undercover Boss'.

Recently, Jennifer can be heard as the voice of 'Dahlia' in Disney's animated feature film, 'WISH'.

She is currently a Communication Studies major at California State University Long Beach.

Thursday, July 10th Keynote Speaker & Thursday, July 10th | 3:00 PM - 3:45 PM | Salon D From childhood to adulthood – disability has shaped who Jennifer Kumiyama is and how she shows up for herself and others like her. She proves that disability is an inherent part of the human experience that affects all communities. Rooted in disabled joy, Jennifer continues to focus on activism that uplifts the disabled community by continuing to fight for equitable legislation at the local, state and federal levels, independent living and intersectional disability visibility.

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.



Thursday, July 10th | 11:15 AM - 12:00 PM | Genetics | Location Salon D - What is a Genetic Evaluation and How Will it Benefit my Child? 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.

SPEAKER SESSIONS



SCAN FOR THE MOST UP-TO-DATE
SPEAKER SCHEDULE



Bio: 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 Universities 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.



Thursday, July 10th | 11:15 AM - 12:00 PM | Hips | Location: Salon D

Contractures of the hip are present in almost 90% of AMC children. Hip dislocations are seen in 30% to 40% of AMC children. The purpose of this talk is to clarify some of the medical jargon that surrounds this complex joint. There is no "one way" to treat an AMC hip, so the aim of this talk is to bring a better understanding of what the surgeon is thinking when planning surgery.



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 could not have gotten this far without the support of his wife, Ana.



Thursday, July 10th | 2:00 PM - 2:45 PM | AMC 101 | Location: Salon D

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 the 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.



SCAN FOR THE MOST UP-TO-DATE
SPEAKER SCHEDULE



SPEAKER SESSIONS

Bio: Don Brown has been in the financial services industry for over 30 years. He has been recognized as an industry leader in both personal production and management. Educating individuals and families on how to properly plan for dependents with special needs is a



Bong Delrosario Accessible Travel

planning may be used to minimize research, to provide protection, government benefits, ongoing requirements & guidelines for use, and funding options. Information will be presented simply and practically on how you might best provide quality of life and a lifetime of care. Participants are welcome to a resource kit and complimentary consultation.

Bio: 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.



Thursday, July 10th | 3:00 PM - 3:45 PM | OB | Location: Salon E

Dr Sara Lemin will present updates in the field of obstetrics and the prenatal diagnosis of AMC. She will review recently published research studies, including surveys that many conference attendees participated in. She will discuss the current guidelines for screening for AMC during pregnancy and opportunities for improvement. She will share new resources, including the 2025 Arthrogryposis New Parent Information Packet.



Arthrogryposis Multiplex Congenita Support, Inc.

amcsupport.org

      @AMCSUPPORT



SPEAKER SESSIONS



SCAN FOR THE MOST UP-TO-DATE
SPEAKER SCHEDULE



Bio: Dr. Kevin Park is a board-certified physician specializing in Spinal Cord Injury (SCI) Medicine and Neurorehabilitation. As an Assistant Professor in the Department of Physical Medicine & Rehabilitation at the University of Utah, Dr. Park plays a pivotal role in adaptive sports community, resident and fellow education, multidisciplinary team leadership, and advanced spasticity management. Beyond the hospital setting, Dr. Park is a strong advocate for adaptive sports and community reintegration, recognizing the critical role recreation plays in the physical and emotional well-being of individuals with disabilities. They are actively involved with TRAILS (Technology, Recreation, Access, Independence, Lifestyle, and Sports), a pioneering adaptive

recreation program at the University of Utah that empowers individuals with complex disabilities to engage in outdoor sports and active lifestyles. Through his work with TRAILS, Dr. Park has helped patients and athletes with disabilities gain access to skiing, handcycling, kayaking, and other adaptive recreational opportunities, emphasizing the importance of functional recovery, independence, and quality of life beyond the clinical setting.



Thursday, July 10th | 4:00 PM - 4:45 PM | Adaptive Sports | Location: Salon D

Join us for an inspiring session highlighting the power of adaptive sports to break barriers, foster inclusion, and enhance quality of life for individuals with disabilities. Through real stories and program examples from the University of Utah's TRAILS initiative, we'll explore how people of all abilities—alongside their families and able-bodied peers—can experience the joy, challenge, and connection that sports provide. Whether on snow, water, or wheels, adaptive recreation proves that the outdoors is for everyone. Come see what's possible when we move together.



Bio: Dr. Arun Hariharan is a pediatric orthopedic and spine surgeon at the Paley Institute, specializing in complex spinal deformities, including those found in arthrogryposis. He completed his medical education at the University of Michigan, followed by an orthopedic residency at the University of Maryland and Johns Hopkins, and pediatric orthopedic and spine fellowships at Nemours/A.I. duPont Hospital for Children and in Auckland, New Zealand. Actively involved in research and education, Dr. Hariharan has numerous publications and presentations and is a member of the Scoliosis Research Society (SRS) and the Pediatric Orthopaedic Society of North America (POSNA). His passion for patient care and innovation ensures the highest quality of care for his patients. Outside of his professional

work, Dr. Hariharan enjoys spending time with his family and cheering for Michigan, Go Blue!

Thursday, July 10th | 4:00 PM - 4:45 PM | Spine | Location: Salon E

Spinal deformities in arthrogryposis present unique challenges due to rigid contractures, poor muscle function, and varied underlying causes. This session will explore modern surgical and non-surgical approaches to managing scoliosis and kyphosis in arthrogryposis, emphasizing the importance of early diagnosis and multidisciplinary care. We will discuss recent advancements in spine surgery, including techniques to maximize correction while minimizing complications in this high-risk population. Topics will include the role of early bracing, surgical strategies such as posterior spinal fusion and growth-friendly constructs, and the impact of spinal alignment on overall function and mobility. Case studies will illustrate decision-making in real-world scenarios, highlighting the balance between achieving correction and maintaining long-term stability. The session will also address ongoing research and emerging technologies aimed at improving spine care for children with arthrogryposis. Attendees will gain insights into optimizing treatment strategies to enhance quality of life for patients with complex spinal deformities.





SCAN FOR THE MOST UP-TO-DATE
SPEAKER SCHEDULE



SPEAKER SESSIONS

Bio: Dr. Noémi Dahan-Oliel is a Clinician Scientist at Shriners Hospital for Children-Canada and has been an Associate Professor at McGill University, School of Physical and Occupational Therapy since 2014. Her research program focuses on improving clinical outcomes for children living with musculoskeletal conditions, specifically arthrogryposis. Research designs include mixed methods, stakeholder engagement, and knowledge translation. Together with a wonderful multidisciplinary and multisite research team, she obtained funding for several clinical research projects in arthrogryposis. These projects include developing a registry for children with arthrogryposis across North America, expanding a registry for arthrogryposis internationally, developing a measure for the upper limb specifically for children with arthrogryposis, and exploring social deprivation and costs of caring in arthrogryposis to improve care and advance research in arthrogryposis



Thursday, July 10th | 5:00 PM - 5:45 PM | AMC Research | Location: Salon D

"Latest evidence on the rehabilitation of children with arthrogryposis: International clinical and lived experience workgroup" Want to learn more about rehabilitation for children with AMC? Our team has partnered with clinicians, people with AMC and families from several countries in the world to co-develop recommendations for rehabilitation. We provide 16 recommendations to address early intervention and motor development, muscle and joint function, orthotics, mobility, participation in areas of life, pain, psychosocial wellbeing, and perioperative rehabilitation. These areas were identified by clinicians, youth with AMC and caregivers as important and were therefore prioritized. We expect that these recommendations will contribute to improving child- and family-centered practice and health outcomes. Next steps include sharing the recommendations and implementing them in practice to promote equity of care. I am looking forward to sharing this work on behalf of our international team.

Bio: Dr. Scott Oishi is the Director of Hand Services in Texas Scottish Rite Hospital for Children's Hand and Upper Limb Service, as well as the Program Director for the 6-mo. Pediatric Upper Extremity Surgery Fellowship Program. He is a Professor in the Departments of Plastic Surgery and Orthopaedic Surgery at the University of Texas Southwestern Medical Center at Dallas. Dr. Oishi grew up in Honolulu, Hawaii, and earned a Bachelor of Science degree in biology at Washington University in St. Louis, Missouri. He earned his medical degree at Tufts University School of Medicine in Boston, completed his general surgery residency at the University of Texas Health Science Center at San Antonio, and his plastic surgery residency at the University of Kentucky Medical Center in Lexington. He completed a hand and microvascular fellowship at the University of Texas Southwestern Medical Center at Dallas and as part of that fellowship, completed a rotation with the Hand Center at Texas Scottish Rite Hospital for Children. Dr. Oishi is a diplomate of the American Board of Plastic Surgery and holds a certificate of Added Qualifications in Surgery of the Hand. Dr. Oishi has made presentations throughout the United States and around the world, and he has authored and co-authored numerous publications.



Thursday, July 10th | 5:00 PM - 5:45 PM | Uppers | Location: Salon E

Treatment of the upper extremities in arthrogryposis - The goal in treatment of the upper extremities in arthrogryposis children is to provide maximum ability for them to perform activities of daily living (ADL's) with the least amount of assistance. Every child has a unique presentation so treatment needs to be individualized based on clinical findings.





Bio: In 2015, **Dr. David Feldman** joined the Paley Institute to lead their 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.



Friday, July 11th | 9:00 AM - 9:45 AM | Mobility | Location: Salon D

The Path to Mobility: Setting Realistic Walking Goals - How to achieve ambulation and how to set realistic goals for the child and their family.

Friday, July 11th | 9:00 AM - 9:45 AM | Mixed Prof. Medical Panel Discussion | Location: Salon E

You know you have questions. We have a panel of experts across multiple specialties ready to discuss your questions and concerns.



Bio: **Ms. Kim Kolstad** 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.

Friday, July 11th | 10:00 PM - 10:45 PM | Adaptive Sports | Location: Salon D

Beyond the Finish Line - How Adaptive Sports Unleash Mental Strength and Unstoppable Confidence," will define adaptive sports through diverse examples. The presentation will delve into how these activities foster crucial social connections, reduce stress, and cultivate profound self-belief and independence. Ultimately, it aims to inspire and empower attendees to explore adaptive sports as a pathway to greater joy, personal growth, and true access within the broader adaptive sports world.



SCAN FOR THE MOST UP-TO-DATE
SPEAKER SCHEDULE



SPEAKER SESSIONS

Bio: Dr. Dan Zlotolow is a Pediatric Upper Limb and Peripheral Nerve Surgeon at The Shriners Hospital for Children Philadelphia and Greenville, and The Hospital for Special Surgery in New York. He specializes in the care of children with Arthrogryposis, brachial plexus and peripheral nerve injuries, spinal cord injuries, complex post-traumatic deformities, congenital differences, and limb deficiencies. He leads medical outreach missions to Havana, Cuba and Kigali, Rwanda and has founded 3 professional societies including Plexus Nexus and the Pediatric Hand International Society of Surgeons (PHISOS). He travels nationally and internationally as a visiting professor and lecturer. He was also a team leader for Zion, the first pediatric hand transplant.



Friday, July 11th | 10:00 AM - 10:45 AM | Pediatric Uppers | Location: Salon E

The old and the new: maximizing independence and function for kids.



Friday, July 11th | 13:00 PM - 3:45 PM | Adult Uppers | Location: Salon E

It's not too late: improving function and appearance in adults

Bio: Dr. Aaron Huser is a pediatric orthopedic surgeon specializing in lower extremity limb deformities and limb length discrepancies in both children and adults. He completed an additional year of training specifically for limb deformity and limb lengthening, and has experience caring for patients with rare or complex disorders that require limb reconstruction.



Friday, July 11th | 11:00 AM - 11:45 AM | Uppers | Location: Salon D

In this session, we will explore surgical treatment options for upper extremity contractures in arthrogryposis, including the goals of surgery, common surgical techniques, and key aspects of postoperative rehabilitation. We will also briefly review surgical considerations for lower extremity contractures. Finally, we'll emphasize the critical role of physical therapy and the importance of maintaining motion in daily life following surgery.

Bio: Dr. Therese Willkomm, PhD, is an Associate Clinical Professor Emeritus in the Department of Occupational Therapy, at the University of New Hampshire. She is known nationally and internationally as the McGyva of Assistive Technology for her rapid and innovative approach in making assistive technology solutions in minutes for living, learning and working. Over the past 40 years, she has created over 2000 different assistive technology solutions; presented over 600 workshops in 42 states and 14 different countries; received many awards including the 2019 RESNA Fellow Award; and authored three books on creating assistive technology solutions in minutes.



Friday, July 11th | 11:00 AM - 11:45 AM | DIY | Location: Salon E

Making, Mounting and Modifying in Minutes with Everyday Materials - This session will discuss and demonstrate over 50 different rapid solutions created for holding: cellphones, beverages, styluses, sandwiches, scissors, ball and dice launchers, cameras, and more. Learn rapid fabrication methods using coroplast, CPVC, Loc-Line, corner guard, twist ties and Instamorph. Discover 8 different tapes for rapid solution creating embracing the "... ABLE" Principles – Adjustable, bendable, removable, washable, portable, affordable, repositionable, and collapsible.





Bio: Driver Rehabilitation Center of Excellence 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.

Friday, July 11th | 2:00 PM - 2:45 PM | Location: Salon D

Driving Rehab Solutions - Featuring 2 recent cases where AMC was the primary diagnosis.



Bio: Dr. Lisa V Wagner DHS, OTR/L received her OT degree from the Medical University of South Carolina and her doctorate from the University of Indianapolis. Working for Shriners Hospitals for Children for the past 34 years has allowed Lisa to participate in various research projects resulting in peer-review articles, book chapter and the ability to speak nationally and internationally. She has co-developed three distinct outcome measures including the UBET, SHUEE and SCUES. She is a clinical instructor for the Assisting Hand Assessment. Passionate about children with AMC, she is currently collaborating on an outcome assessment for better understanding of the upper extremities.

Friday, July 11th | 2:00 PM - 2:45 PM | OT | Location: Salon E

Adventures in Autonomy - 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 evermore connected world. Come ready to share and discuss your quest for autonomy.



amcsupport.org

f @AMCSUPPORT





SCAN FOR THE MOST UP-TO-DATE
SPEAKER SCHEDULE



SPEAKER SESSIONS

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: My name is **Chloe Sutterfield**. I'm from Aylett, Virginia. I am attending James Madison University for grad school and will be studying communications and advocacy. I am also a musician, public speaker/advocate, actress, writer/published author, and I play lots of adaptive sports.



Friday, July 11th | 3:00 PM - 3:45 PM | College Transition! Location: Salon D

There are many new words and ways things are done in college – especially for a student with a disability. What's Different? How do you get help? What does ____ mean? Why go on a college tour? Who at college can help me? This presentation, "Beyond the Threshold: Embracing College Opportunities," is designed to initiate those conversations. Through interactive discussion, hearing from experts – students with disabilities navigating college, research, and professional knowledge – we'll discuss the college experience. We will explore the differences between college and high school, provide practical tips for college preparation, help you become confident in exploring various college options, and offer a chance to ask those burning questions about college. This presentation is designed to help students and their families understand what comes after graduation and how to navigate that transition with a plan for success.





Bio: 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.

Friday, July 11th | 4:00 PM - 4:45 PM | AMC & Pain | Location: Salon D

AMC and Pain: What we know so far with strategies to support care – Pain perception is unique to each individual but what we know is that those who have AMC experience pain. This session will delve into the types of pain that can be experienced and work on some non-medication based strategies to support care.



Bio: Dr. Stephanie Russo is a Pediatric Upper Limb and Peripheral Nerve Surgeon and Akron Children's Hospital in Akron, Ohio. She specializes in caring for children with brachial plexus and other nerve injuries, spinal cord injuries, arthrogryposis, spasticity, and congenital hand differences. Dr. Russo directs the Motion Analysis Laboratory at Akron Children's Hospital. In this role, she mentors graduate students and collaborates with several other institutions for research projects. Outside of work, Dr. Russo enjoys travel, food, ballet and volunteer work.

Friday, July 11th | 4:00 PM - 4:45 PM | Uppers | Location: Salon E

Every person with arthrogryposis has unique needs to optimize their functionality. This presentation will address surgical options to improve wrist, hand, and thumb function in patients with arthrogryposis. Considerations for determining who is an appropriate candidate for surgery will be discussed. Participants will gain better understanding of upper limb treatment options. The need for individualized goals and treatment plans will be highlighted.



AMCSI



Arthrogryposis Multiplex Congenita Support, Inc.

amcsupport.org

@AMCSUPPORT



FULL SCHEDULE



SCAN FOR THE MOST UP-TO-DATE
CONFERENCE SCHEDULE



WEDNESDAY, JULY 9, 2025

TIME	SESSION	ROOM
2:30 PM - 3:30 PM	Volunteer Training	4th Floor Foyer
4:00 PM - 6:45 PM	Registration/T Shirt pick up	4th Floor LOBBY
	AMC Store	4th Floor LOBBY
	Vendors	4th Floor LOBBY
	Auction	Salon A
7:00 PM - 8:15 PM	First-Time Attendees	Paul D. Fraim Center for Excellence
8:15 PM - 9:00 PM	Preteen/Teen Meetup	Outside of the Paul D. Fraim Center for Excellence
7:30 PM - 10:00 PM	Informal Social Time for All Attendees	
	Hotel Lobby/Bar	Food & drink on your own



THURSDAY, JULY 10, 2025

TIME	SESSION	ROOM
8:00 AM - 6:00 PM	Registration/T Shirt pick up	4th Floor LOBBY
	AMC Store	4th Floor LOBBY
	Vendors	4th Floor LOBBY
	Auction	Salon A
10:00 AM - 10:45 AM	Opening Ceremony - Jennifer Kumiyama	Salon D/E
11:15 AM - 12:00 PM	Adults With AMC Co-Ed	Salon B
	Dr. Phillip Giampietro - Genetics	Salon D/
	Dr. Reid Nichols - Hips	Salon E
	Tween Girls	Salon H
12:00 PM - 2:00 PM	Lunch (on your own)	
12:30 AM - 2:30 PM	BOD Office Hours	Exchange 6
2:00 PM - 5:45 PM	Children's Programming	Salon F/G
2:00 PM - 2:45 PM	Sib Shop	Salon B
	Dr. Harold J.P. van Bosse - AMC 101	Salon D
	Bong Delrosario - Accessible Travel	Salon E
	Tween Boys	Salon H
3:00 PM - 3:45 PM	Teen Girls	Salon B
	Jennifer Kumiyama	Salon D
	Dr. Sara Lemin - OB	Salon E
	Moms Of AMCs	Salon H
4:00 PM - 4:45 PM	Dads Of AMCs	Salon B
	Dr. Kevin Parks - Adaptive Sports	Salon D
	Dr. Arun Hariharan - Paley	Salon E
	Teen Boys	Salon H
5:00 PM - 5:45 PM	Dr. Noémi Dahan-Oliel - Research	Salon D
	Dr. Scott Oishi - Uppers	Salon E
6:45 PM - 8:00 PM	Dinner	The Granby Ball Room

(One level DOWN from the meeting space)

Schedule continued on Pg. 18



the most
AMAZING
CARE
anywhere™

Shriners Children's brings a compassionate, innovative team approach to caring for children with arthrogryposis. Our goal is your goal: giving your child the best quality of life possible.



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



Shriners
Children's™

FULL SCHEDULE



SCAN FOR THE MOST UP-TO-DATE
CONFERENCE SCHEDULE



FRIDAY, JULY 11, 2025

TIME	SESSION	ROOM
8:00 AM - 5:00 PM	Registration/T Shirt pick up	4th Floor LOBBY
	AMC Store	4th Floor LOBBY
	Vendors	4th Floor LOBBY
	Auction	Salon A
10:00 AM - 4:45 PM	Children's Programming	Salon F/G
9:00 AM - 9:45 AM	Dr. David Feldman - Lowers	Salon D
	Mixed Medical Panel Discussion	Salon E
10:00 AM - 10:45 AM	Moms Of AMCs Under 10	Salon B
	Ms. Kim Kolstad - Adaptive Sports	Salon D
	Dr. Dan Zlotolow - Pediatric Uppers	Salon E
11:00 AM - 11:45 AM	Men With AMC	Salon B
	Dr. Aaron Huser - Lowers	Salon D
	Dr. Therese Willkomm - DIY	Salon E
	Woman With AMC	Salon H
12:00 PM - 2:00 PM	Lunch (on your own)	
12:30 AM - 2:30 PM	BOD Office Hours	Exchange 6
2:00 PM - 2:45 PM	Adults With AMC Dating	Salon B
	Driver Rehabilitation	Salon D
	Dr. Lisa Wagner - OT	Salon E
3:00 PM - 3:45 PM	Grandparents Of AMCs	Salon B
	Ms. Jan Shea - College Tranistion	Salon D
	Dr. Dan Zlotolow - Adult Uppers	Salon E
	Gay Straight Alliance	Salon H
4:00 PM - 4:45 PM	Parenting With AMC	Salon B
	Dr.Maureen Donohoe - Pain	Salon D
	Dr. Stephanie Russo - Uppers	Salon E
7:00 PM - 9:00 PM	AMCSI Prom Bubbles Themed	The Granby Ball Room (One level DOWN from the meeting space)
9:00 PM - 11:00 PM	Set up for Painting with Theresa	Salon G/H



SATURDAY, JULY 12, 2025

TIME	SESSION	ROOM
8:00 AM - 2:00 PM	AMCSI Store	4th Floor LOBBY
9:00 AM - 12:00 PM	Silent Auction, All Bidding Ends at Noon	Salon A
	BOD Office Hours	Exchange 6
9:00 AM - 10:00 AM	Group Photo	Salon D/E
10:00 AM - 11:45 AM	Painting with Theresa	Salon G/H
11:00 AM - 11:30 AM	BOD Annual Meeting	Salon D/E
11:45 AM - 12:45 PM	Closing Ceremony, performance by Luca "Lazylegz" Patuelli Recap Slide Show, & Announcements of 2026/2027	Salon D/E



SLEEP MADE SAFE



the safety sleeper®

BY ABRAM'S NATION



AN ENCLOSED BED DESIGNED FOR
INDIVIDUALS WITH SPECIAL NEEDS



Convertible Entry



End of Bed Entry



Standard Side Entry

CALL: 724-967-5337

EMAIL: CUSTOMERCARE@ABRAMSNATION.COM

TO LEARN ABOUT COVERAGE OR PRIVATE PAY OPTIONS





CHILDREN'S PROGRAMMING IN HONOR OF BRIAN WAYNE PAGE

THURSDAY, JULY 10, 2025

TIME.....SESSION & DESCRIPTION Salon F/G

2:00 PM & 3:00 PM Make-It Take It (Part 1 & 2)

Have fun exploring outer space with space-themed crafts and fun activities. Part 1 and Part 2 are the same session – please choose the one session that best fits your schedule

4:00 PM & 5:00 PM Blast Off To Space - Glow Party (Part 1 & 2)

Blast off to Space for our annual glow party! Come get some glow gear and dance the afternoon away with glow sticks, black lights and music. This is a drop in session – stay for as long or as short of a time as you like during the two hour session.



FRIDAY, JULY 11, 2025

TIME.....SESSION & DESCRIPTION Salon F/G

10:00 AM Teddy Bear Clinic with Child Life at the Paley Institute

Come be the doctor for the day and make your own stuffed animal to care for! All ages of kids and teens welcome to come and stuff your own bear! Sponsored by Dr. Feldman and the unLIMBited Foundation.

11:00 AM Story Time With Tammy

Who wants to hear a story? Join Ms. Tammy for an interactive story time with lots of fun books and stories. All ages welcome.

2:00 PM Music With Chaney

An AMC conference favorite! Join Chaney Roko for a sing-along of your favorite songs! Kids of all ages are welcome to come sing and dance.

3:00 PM & 4:00 PM Game Time With Your Favorite Doctors & Therapists (Part 1 & 2)

Attend Part 1, Part 2, or both! This session will continue for 2 hours with no break in between. All doctors, therapists, and other medical professionals are invited to come play games with our kids and families. Drop in for as long as you like. Have fun playing games with new friends, building with legos or magnet blocks, or just hanging out in a fun social space. This is a fun, unstructured time to play games with other AMC families.



>>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.

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

Kids must have an adult (ages 16 or up) with them at all times, including 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 #AMCVA25 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. AMCSI reserves the right to enforce the code of conduct.



amcsupport.org
f i s t v X @AMCSUPPORT



S'MORES AMORE

We're turning up the YUM at this year's 20th Annual AMCSI Conference in Norfolk, VA – July 9-12!

Get ready to indulge in a delicious treat from our friends at S'MORES AMORE – all in honor & memory of our beloved Brian Wayne.

Every attendee will receive a special ticket to redeem their ooey-goey goodness next door. Trust us – your tastebuds will thank you!



Amalgamated Medical Company Support, Inc.

@AMCSUPPORT



Thank You To Our Sponsors

Platinum Sponsor



Shriners
Children's™

Silver Sponsors

The Bulsiewicz Family Donation



ABLEnow®

Children's Programming Teddy Bear Clinic Sponsor



Grant Awarded to AMCSI



Sponsor of Painting with Theresa

BLICK
art materials

Adaptive Sports Sponsors

TRAILS

TECHNOLOGY • RECREATION • ACCESS
INDEPENDENCE • LIFESTYLE • SPORTS



The Adaptive Sports was made possible through the donation made by the Members of the Louisiana Club

Patron Sponsors

Matthew & Julie Cavedon

Ewa Okla

Dr. Reid Nichols

Gianmarco Martuscelli The Martuscelli Restaurant Group



July 9 – 12, 2025 | #AMCsupport #Strength #Resilience #Courage

CONFERENCE MAP



KEY

-  MEETING/CONFERENCE ROOMS
-  AMENITIES
-  ELEVATOR



Conference Hours

Wednesday, July 9th
4:00 pm - 10:00 pm

Thursday, July 10th
8:00 am - 8:00 pm

Friday, July 11th
8:00 am - 9:00 pm

Saturday, July 12th
8:00 am - 1:00 pm



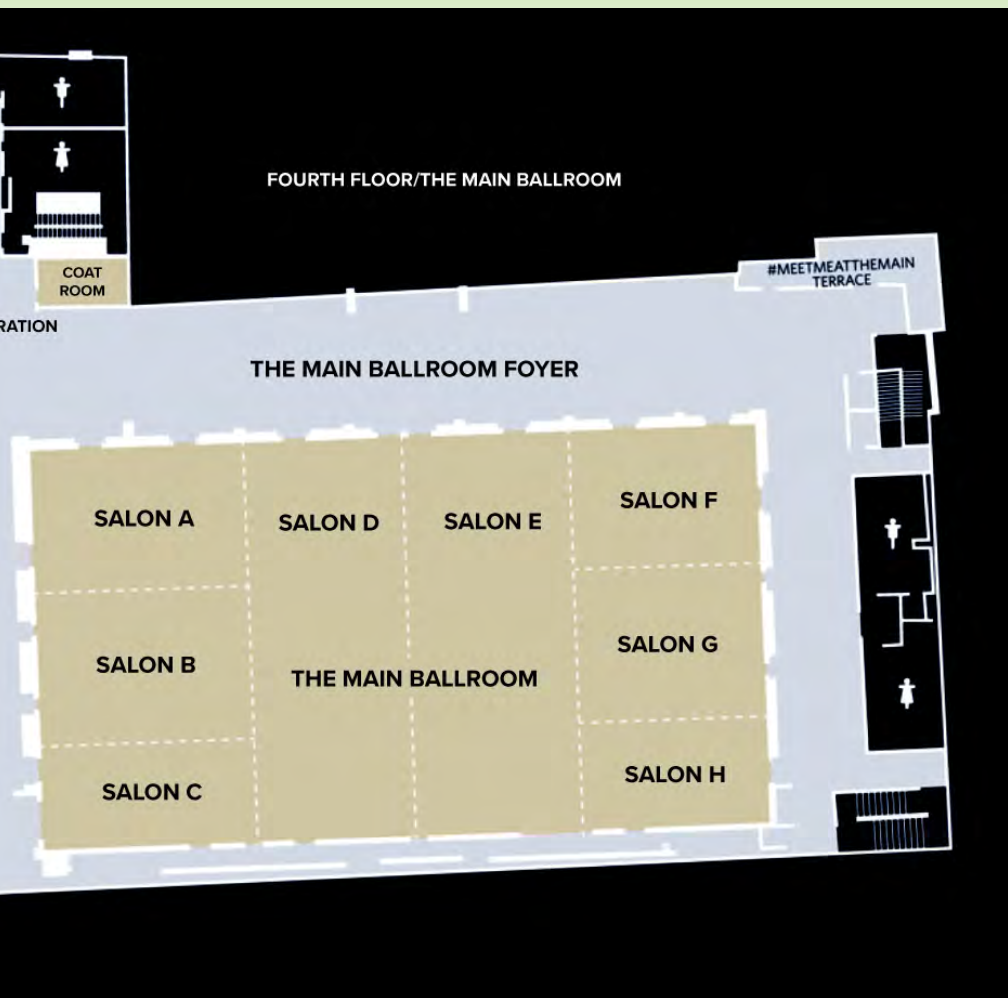
Arthrogryposis Multiplex Congenita Support, Inc.

20th Annual
Arthrogryposis Multiplex Congenita
Support Inc. Conference
July 9 – 12, 2025

SCAN FOR THE FULL
CONFERENCE SCHEDULE



CONFERENCE MAP



Conference Hours

Wednesday, July 9th
4:00 pm - 10:00 pm

Thursday, July 10th
8:00 am - 8:00 pm

Friday, July 11th
8:00 am - 9:00 pm

Saturday, July 12th
8:00 am - 1:00 pm



Arthrogryposis Multiplex Congenita Support, Inc.

20th Annual
Arthrogryposis Multiplex Congenita
Support Inc. Conference
July 9 – 12, 2025

SCAN FOR THE FULL
CONFERENCE SCHEDULE



BOARD OF DIRECTORS



ALEXIS RECORD
President



Alexis Record lives in San Diego with her husband, Charles Wesley, their two kids, three kitties, and occasional foster kittens. Her daughter, Laelia, was born in 2007 with the amyoplasia type of AMC and her daughter, Violet, was added to the family in 2012 with the distal 2E type of AMC. Alexis is the executive director of Sunday Assembly San Diego, a non-religious inclusive community that does a lot of community 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 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
Member-At-Large

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



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.



MARK INDREIKA - *Member-At-Large*

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."



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*

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 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.



MEDICAL ADVISORY BOARD



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.



Arthrogryposis Multiplex Congenita Support, Inc.

amcsupport.org

      @AMCSUPPORT



AMCSI INTERNATIONAL AMBASSADOR

MISHA “DREAM” WALKER

International Ambassador

Misha “Dream” Walker from Arequipa, Peru, was born with Arthrogryposis. Now living in Lima, Peru, Misha works as an insurance broker and as an Inspirational speaker/blogger as part of her “Dream Walker” project. Misha devotes her life to helping others in need of guidance, and raising awareness for AMC globally and by using her life experiences to inspire people to seize the opportunities offered to them. Misha is an advocate for people with disabilities, motivating them to alter their view of the world around them and how to interact with it, and embrace their lives to the fullest, whilst also pushing to reshape the world’s view of what it means to be disabled. On her free time, Misha likes to go the beach with her husband, spend time with friends and paint, she also loves music and fast cars.



CONFERENCE PLANNING COMMITTEE



MICHELE SCHAFFER



**BETSY
GATES-EHLERS**



MAUREEN GOEDE



ANA VAN BOSSE



JAN SHEA



**LARINA SWANSON-
CARTER**



BETH SELLERS



STAFF



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.



JENNIE PARADEIS
Administrative Assistant

Jennie Paradeis is a proud AMC mom to daughter Dylann. She holds a Master's degree in Counseling Psychology and one in Business Administration. She is program manager at a non-profit health plan overseeing a program that serves Minnesotans who are on a state disability product. Starting in 2015, Jennie hosted a charity 5k event with the goal of raising awareness for AMC and providing financial support for AMCSI for 5 years before joining the board in 2019 . In her spare time

Jennie enjoys reading, traveling, and spending time with her family. She currently resides in Minnetrista, MN



TED HOUSER
I. C. - Professional Graphic Design Production Artist

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 design. 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.



Thank you Misha & Mike!



View the full photo recap gallery at:

<https://amcsupport.org/mishas-long-road-to-amc-awareness-2025/>



Arthrogryposis Multiplex Congenita Support, Inc.

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 is valid from JANUARY 1st through DECEMBER 31st

[HTTPS://AMCSUPPORT.ORG/BECOME-A-MEMBER/](https://amcsupport.org/become-a-member/)



Follow Us

@AMCSUPPORT



Thank You To Our Exhibitors

(Some of the Exhibitors are also Sponors)



Shriners
Children's™

ABLEnow.

TRAILS

TECHNOLOGY • RECREATION • ACCESS
INDEPENDENCE • LIFESTYLE • SPORTS



Project Lightning Bug



the safety sleeper®

THE SAFETY SLEEPER IS A REGISTERED TRADEMARK

**UNIVERSITY OF
DELAWARE**



DRCE
It's not just driving



BEYOND BOUNDARIES
ADVENTURE IS FOR EVERYONE



**PARTNERS IN
MEDICINE**



Alora Grove
Soothe. Nourish. Thrive.



Thank you to all of our incredible exhibitors for being part of the 20th Annual
AMCSI Conference!

Your presence, knowledge, and support help us build connection, community, and
access to resources for the
AMC community.

We're grateful for your partnership and commitment.



AMCSI July 9 – 12, 2025 | #AMCsupport #Strength #Resilience #Courage

BLYSS Ice Cream & Desserts — located right around the corner next to Rolled Up and near the Hilton — is excited to support the AMCSI Conference!



From July 9–12, conference attendees can enjoy \$5 off their sweet treats with a special coupon, courtesy of BLYSS. Coupons will be available at the conference — stay tuned!

Accessibility Note: The shop entrance has two manual doors, which may present challenges for some wheelchair users. However, there are no stairs at the entrance.

We're grateful for their support — and can't wait for you to treat yourself!



@AMCSUPPORT
f i b t y x

With Deepest Gratitude to Our Fundraisers

To every individual, family & team who has fundraised 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**
- **The Brayden Dame Scholarship**
- **Accessibility, Adoption, Bereavement, Medical Travel, Mini-Meetup & Research Grants**
- **And the unforgettable AMC Holiday Grant**—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 how you 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.





TBSDesigns has a deep understanding of design principles, color theory, & brand management, we combine creativity & precision to deliver designs that not only capture attention but also tell a compelling story, strengthen brand presence, & leave a lasting impression.

Logo Designs



Web Designs



Ted Houser / ted@tbsdesigns.com

Artist / Professional Designer / Web Builder

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 design. 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.



Project Lightning Bug

Be the voice for the voiceless.



Gifts with Heart!



From one-of-a-kind t-shirts, mugs, and holiday gift baskets, to key rings, pens, mini bags, car fresheners, and so much more — we've got something fun for everyone!

🌟 Visit us at: facebook.com/projectlightningbug

Project Lightning Bug was created to spark joy, strengthen community advocacy & support individuals living with disabilities. ❤️



DRCE

At Driver Rehabilitation
Center of Excellence, LLC,
we know that

"It's not just driving."

Our mission is to deliver exceptional,
personalized services that address the
unique driving needs of each client



Personalized Client Support Services

- Comprehensive Evaluations - Drivers & Passengers
- On-the-Road Training Program
- Full Service Adaptive Equipment Installations
- Custom Fabrication & Mobility Solutions
- Accessible Vehicle Consultations



Regain Your Driving Independence

703.345.2990



info@driverrehabcenter.com

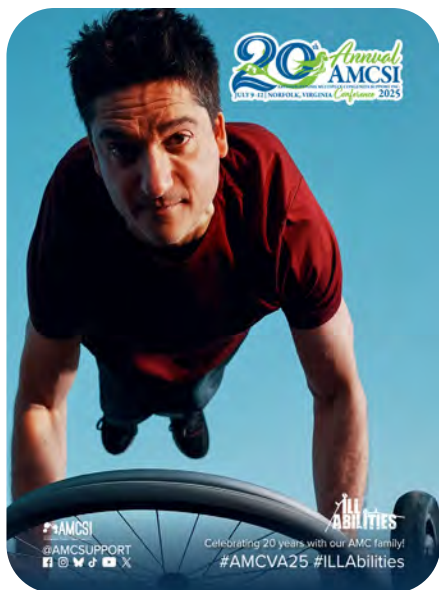


driverrehabcenter.com



BEYOND BOUNDARIES

ADVENTURE IS FOR EVERYONE



AMCSI is honored to welcome Luca “Lazylegz” Patuelli as our special guest at the 20th Annual AMCSI Conference!

Luca is a world-renowned breakdancer, motivational speaker, and the founder of the ILL-Abilities™ International Dance Crew — redefining what’s possible through the mantra “No Excuses, No Limits.”

Born with arthrogryposis, Luca has inspired audiences across 22+ countries with his dynamic performances and powerful message of perseverance, creativity, and inclusion. His work has been featured on The Ellen Show, America’s Got Talent, the Special Olympics in France, and many other global stages.

Thank you, Luca, for bringing your energy, passion, and artistry to the AMCSI community — your impact is unforgettable!

Save today for a better tomorrow

ABLEnow®

Tax-advantaged savings accounts that won’t impact certain disability benefits

ABLEnow.com



Call 1-844-NOW-ABLE or visit ABLEnow.com to obtain information and all program materials. Seek the advice of a professional concerning any financial, tax, legal or federal or state benefit implications related to opening and maintaining an ABLEnow account. Participating in ABLEnow involves investment risk including the possible loss of principal. ABLEnow is administered by Commonwealth Savers Plan. For non-Virginia residents: other states may sponsor an ABLE plan that offers state tax or other benefits not available through ABLEnow. © 2025 Commonwealth Savers Plan. All Rights Reserved.

Loon Crew:

Thank you so much for the time and effort you put into organizing our conference. The endless hours and your passion are what makes the event a success. I am so Thankful that I have each of you on this team, Your support and collaboration are what makes this event so special. Thank you from the bottom of my heart!

- Michele



2025

TST-Thank you for your continued support. I could not do this without you. I love you. MLS



Hilton
NORFOLK THE MAIN

The Planning Team and Board of Directors of Arthrogryposis Multiplex Congenita Support, Inc. would like to express our gratitude to the staff at the Hilton Norfolk - The Main. We appreciate their help and support in making the 20th Annual AMCSI Conference a success. Thank you.

Alora Grove

Our goal is to empower individuals on their healing journey by providing natural, energy-infused products that offer effective, holistic pain relief. We are dedicated to enhancing well-being through carefully crafted, alternative solutions that promote healing, comfort, and vitality.

Pain Relief Salve

Our salve helps relieve pain through a combination of essential oils and natural ingredients, infused with pranic healing energy.

Pranic Healing Sessions

Our pranic healing sessions relieve pain through life force energy to balance, harmonize and transform the body's energy systems.



Alora Grove

Soothe. Nourish. Thrive.

Website: www.aloragrove.com

Email: aloragrove@gmail.com

Instagram: [@aloragrove](https://www.instagram.com/aloragrove)



**PARTNERS IN
MEDICINE**

**Hey AMCs –
want to try the
Jaco Robotic
Arm?**

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



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 10:00 - 11:45
Location Salon G/H

Chris Hartwick is an artist and graphic designer living with Arthrogryposis Multiplex Congenita (AMC), which limits the use of his arms and hands. From an early age, he taught himself to draw and paint using his mouth — a passion that led to a B.S. in Graphic Design from Bob Jones University.

Chris has worked in animation and now serves as a graphic design specialist at a university, while also freelancing. His award-winning artwork has been exhibited locally, statewide, and nationally, with eight paintings published to date.

In 2007, he co-founded the Artists Guild Gallery of Greenville, where he continues to contribute as a designer and member.

Chris encourages everyone to focus on their abilities — not limitations — and embraces life fully through art, sports, and hobbies like swimming, cooking, and building with LEGO.

Chris will be face-painting on Saturday from 10:00 - 11:45 | Location Salon G/H



Thank you...

To Our Volunteers, Session Moderators, and Scholarship Donors

The 20th 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.

This year's AMCSI Conference Scholarships were made possible through the generous contributions of: Ewa Okla, Doug Moreau & the Members of the Louisiana Club, Paul Eterno Memorial Fund.

The Brayden Dame Scholarship was proudly supported by the Calvin and Marissa Allen Foundation.

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 20th 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



"We are so proud of all you have achieved, Lauren. Lots of love!" - Mom & Dad



**Breaking
Barriers
&
Enriching
Lives**



More Than an Appointment

It's a confidence boost.

Frankie, a 5 year old born with athrogryposis multiplex congenita (AMC), experiences joint stiffness in her extremities that reduces her mobility and makes everyday tasks more challenging.

But through our collaborative approach to treatment that includes bracing, physical and occupational therapy, stretching, and surgery, the experts at Nemours Children's Hospital, Delaware have given her the confidence to thrive.

"The team always builds Frankie up and focuses on her strengths," says her mother Lindsay. "She walks out of her appointments standing a little taller and feeling good about herself."

Today, Frankie is playing soccer and does dance — proof that she's not letting anything hold her back.

**Your child is more than their diagnosis.
And we're more than a hospital.**

Learn more about our world-renowned pediatric orthopedics program at Nemours.org.



Well Beyond Medicine