VIVA LAS VEGAS

12th Annual
Arthrogryposis Multiplex Congenita Support Conference
June 28 - July 1, 2017
Las Vegas, NV
www.amcsupport.org
#amcvegas17
For over 90 years, Shriners Hospitals for Children has been devoted to transforming the lives of children through excellence in quality care, teaching and research. Located at 3551 North Broad Street, Shriners Hospitals for Children — Philadelphia provides care to children with orthopaedic conditions, spinal cord injuries, and comprehensive and individualized rehabilitation program needs. Children from birth to 18 are eligible for care. Acceptance is based solely on a child’s medical needs, regardless of the families’ ability to pay. For more information,

“Drs. Harold van Bosse, Scott Kozin and Dan Zlotolow, and the Shriners Hospital for Children - Philadelphia, support the Arthrogryposis Multiplex Congenita Support, Inc. and its mission of providing and encouraging understanding and support for those with Arthrogryposis Multiplex Congenita, as well as creating awareness of AMC. We are so proud of all our AMC patients, and feel uniquely privileged to participate in their journey.”

For appointments at Shriners Hospitals for Children - Philadelphia
215.430.4140 or PHLnewappts@shrinenet.org
shrinershospitalsforchildren.org/philadelphia
Dear AMC Family,

It gives me great pleasure to welcome you all to Las Vegas, Nevada for the 12th Annual AMCSI Conference. This weekend will be full of great information, networking and support. Our schedule is full of great presentations, support sessions and many activities for your children to enjoy. AMC Awareness Day is on June 30th. I am thrilled to share this day with all of you to celebrate all of our AMCers. Please don’t forget to wear blue on Friday!

I would like to extend my warmest welcome to our first time attendees. I know that this weekend will be overwhelming for many of you. Please take our schedule at your own pace. There will be many of us who will be able to assist you, should you have any questions. We hope that this weekend will be memorable for all of you.

A very warm welcome to all of our speakers, presenters, and vendors! We thank each of you for your generous contribution to our annual conference.

We could not host our annual conference without the generous donations from our sponsors, donors, annual fundraisers, friends and family. From the bottom of my heart, thank you.

A very special thank you to our Board of Directors and our conference planning team, for your commitment to our AMC community and your dedication each year to our annual conferences. To all of our committee members and volunteers, thank you for your countless hours of work behind the scenes and at conference. Because of all of you, we are able to provide our AMC families all over the world valuable information and support.

I am thankful for each and every one of you who traveled the many miles to be with us in Las Vegas. I am excited to meet all of our new AMC families and look forward to all of us having an amazing weekend together.

Sincerely,

Ani Samargian,
Founder Arthrogryposis Multiplex Congenita, Support, Inc.
Dear Friends,

The 2017 Conference Committee would like to welcome you to the 12th Annual Arthrogryposis Multiplex Congenita Support, Inc. conference in Las Vegas, Nevada! We are so happy that you are here, this year is one of our largest conferences to date with over 600 attendees, speakers and staff registered! If you are a first-time attendee, WELCOME! We realize that your first conference can be overwhelming, please know we were all first-time attendees at one time! If you are feeling “lonely,” please find one of the planning team or a board member, and we will do our best to make you feel welcome!

We would like to extend our thanks to all of you who have offered to share your time as a volunteer. We could not offer the programming that we do without your help. From Children’s Programming to the Silent Auction and Store, Volunteers are who make it happen. We can plan, but without YOU we couldn’t follow through.

Over the next three days, you will have the opportunity to participate in a variety of sessions. We have planned a diverse schedule in the hope to provide information and support to all who attend. Please remember that all of our presenters volunteer their time and travel, so please offer them your thanks. While we understand that many of you may wish to engage them in conversation; please respect their time and the time of your fellow attendees. We believe that the support sessions at the conference are just as important as the sessions that offer medical information. These gatherings provide a safe environment for people to share and support those walking a similar path. For the comfort of all, we request that you please honor the privacy of these sessions and only attend the ones that personally apply to you.

We understand that the planned schedule may not meet the needs of individual families, please do not worry! We want the conference to be a comfortable experience for all, so do what is best for your family. Most importantly, we hope you enjoy your time with us, and that you have the opportunity to spend time with friends, both old and new.

Warmly,

Michele Schaffer, Jean Balent-Gephardt, Betsy Gates-Ehlers
Vice-President of Programming Director of Operations Director of Logistics

LaShell Page, Ani Samargian
Director of Children’s Programming Founder

La NOTE FROM THE 2017 CONFERENCE PLANNING COMMITTEE
My name is Lana Prater.

I am so honored to introduce myself as your new AMCSI President.

Before telling you a little about myself, I’d like to take a moment to thank our previous President, Theresa Lucas. “Thank you Theresa for your many years of commitment and for making Painting with Theresa such an immeasurable success. I hope to do you proud as I take on this exciting new role.”

A little about myself. I am an AMCer; and I have an intense passion for this organization. I live in Lewiston, Idaho, with my husband Delmer, our English Mastiff, Kodiak, our Chiweenie, Shtiya, a koi pond, fish tank and two peacocks. I enjoy singing and preparing large meals for friends and family. My husband and I have five children and six grandchildren.

My first conference was Vegas 2013. I ugly cried for three days. Every photo of me was with a red nose and tears in my eyes. I was overwhelmed meeting people like me. By the end of that first conference I knew I wanted to be a part of AMCSI. I became a Member at Large, then Secretary, and now President. Get used to this face because you’ll be seeing it a lot—and for a long time.

I’d be lying if I said it’s an easy job. There’s a lot to do. We are currently working on different grant programs. We have thousands of dollars earmarked for programs like our scholarship fund for AMCers going into college. Our adoption fund, our research fund and our bereavement fund, just to name a few. It is my goal as your president to have all these programs up and running by the beginning of 2018.

We are working on a new user-friendly website as well as pamphlets about Arthrogryposis to give to hospitals, doctor’s offices and new or expecting parents of an AMCer. I have lots of new and exciting ideas to present to the board for discussion and possible implementation. I’m so excited to see what we can do in the near and distant future.

I am always open to hear from you with your ideas because you are why we do this. I thank you for your support and would like to encourage you to take a moment when you see our staff to thank them for volunteering their time and energy, putting in endless hours of work to make this amazing organization run.

Thank you,

Lana Prater,
President Arthrogryposis Multiplex Congenita Support, Inc.
KEYNOTE SPEAKER

DR. NOÉMI DAHAN-OLIEL, PHD

Noémi is an occupational therapist by training, and obtained her PhD in Rehabilitation Sciences from McGill University in 2014. She is a clinician scientist and coordinator of the clinical research department at Shriners Hospital for Children – Canada, and Assistant Professor at McGill University, School of Physical and Occupational Therapy. Her clinical and scientific work have focused on improving quality of life and function for children with different types of physical and neurological disabilities.

Presentation: Touched by the challenges that children with AMC and their families face, I was encouraged to develop research efforts for children with AMC in 2015 by my mentor at Shriners Hospitals for Children (SHC) - Canada, Chief of Staff, Dr. Hamdy. A planning grant funded by the Canadian Institutes of Health Research provided me with the platform to develop a network of North American experts in AMC. This was the start of an exciting journey and together, research priorities were set and received funding from different agencies. Research efforts include a population database for children with AMC which is being developed collaboratively at SHC-Canada and SHC-Philadelphia with Dr. Harold vanBosse. As well, other projects focus on innovation in rehabilitation practice, multidisciplinary care, patient engagement, and knowledge exchange with youth, families and clinicians, all of which I am delighted to share with you.

Focus group with parents of children with AMC: We would like your opinion on rehabilitation services, including referral process, treatment plan and communication. Your feedback will help us develop practice recommendations for rehabilitation.

PRESENTERS

DONALD BROWN, CHFC®, CASL®, LUTCF

Don has been in the financial services industry for the past 31 years. Educating individuals and families on how to properly plan for a dependent with special needs is a primary focus of Don's practice. Don demonstrates a broad, long-standing commitment to local community and philanthropic service. He is an over 20-year volunteer with Camp Fatima of New Jersey, an all-volunteer one on one camp for developmentally challenged children. Don is a graduate of Rutgers University with a degree in Economics and Finance and holds his series 6, 7, 63 and 24 security licenses along with his life, annuity, accident and health licenses, and LUTCF, CASL and ChFC designations.

Presentation: Families with dependents with special needs, no matter what the age, face many serious questions about how to best prepare for their future well-being. This workshop will address such critical issues as protecting government benefit eligibility for SSI, creating special needs trusts, and the importance of a will. Taking steps now can help a loved one's well-being today and tomorrow.
MAUREEN CASEY

Maureen Casey and her husband David, have three children, including one with AMC. Maureen serves the Arizona Department of Economic Security (DES) as the Bureau Chief for the Arizona Early Intervention Program (AzEIP), within the Division for Developmental Disabilities. Through a network of stakeholders and partners, the Division plays an important role to support families of infants and toddlers with disabilities to help their children grow and develop, and connects them to community resources. Maureen began her career with the Department of Economic Security in 2013, as a Continuous Quality Improvement Coordinator. Over the last three years she has been in a series of roles which have enabled her to use her passion for data and systems-thinking to support staff to more efficiently serve the families supported by the Department. A nationally recognized expert on children with disabilities, she presents often on how systems can use data to improve outcomes for children and their families. Maureen has a Bachelor’s of Arts from Marist College and a Master of Arts from Fordham University.

Presentation: Plans: what are they, how to prepare and how to track their success in meeting your child's needs.

TRICIA CATALINO, PT, DSc, PCS

Tricia Catalino, PT, DSc, PCS is an associate professor of the School of Physical Therapy at Touro University Nevada. During her 20 years of practice, Dr. Catalino has served children with disabilities and their families in the early intervention (EI) setting. She is an ABPTS pediatric clinical specialist and the Chair of the APTA, Academy of Pediatric Physical Therapy, EI Special Interest Group. She is a Fellow-in-Training in the APTA Education Leadership Institute and is the Physical Therapy Coordinator for NvLEND - Nevada Leadership Education in Neurodevelopmental and Related Disabilities program. Dr. Catalino is a member of both the Division for Early Childhood (DEC) Recommended Practices Commission and the DEC Executive Board. She received her BS and MPT degrees from Northwestern University and her MS and DSc degrees from the University of Oklahoma Health Sciences Center.

Presentation: Recommended Practices for Early Childhood Intervention. The Division for Early Childhood (DEC) is an international membership organization that promotes policies and advances evidence-based practices that support families and young children who have or are at risk for developmental delays and disabilities. The DEC Recommended Practices were developed to provide guidance on practices related to better outcomes for young children with disabilities and their families. In this session participants will learn about the DEC Recommended Practices and discuss how to implement the practices in the early intervention and early childhood special education settings. Participants will also learn about the background and evidence for the practices and take part in discussion about how the practices can help support families through collaboration with team members.

CHRISTINA CROWDER, RDN

Christina is a Registered Dietitian/Nutritionist at the University of Oklahoma Physicians Diabetes and Endocrinology Clinic in Tulsa, Oklahoma, specializing in pediatric endocrinology. A majority of her practice is spent working with children who have complex health care needs requiring enteral feeding management. She also is engaged in the clinic Type 1 Diabetes research and has a passion for furthering evidence-based practice through research. Outside of the clinic, she volunteers with the University of Tulsa as a sports dietitian; consults
with USA Gymnastics; and is very active within her church. She recently started a private consulting practice, Christina Crowder-RDN LLC.

Presentation: Blenderized Tube Feeding and Failure to Thrive Challenges. Today, “real food” and “clean eating” trends have prompted parents and professionals alike to seek out alternative tube feeding formulas that don’t contain corn syrup solids and vegetables oil as the first two ingredients. If not for the sake of “real food”, children at times will poorly tolerate standard formulas leading to gagging, retching, and poor weight gain. Recently, a few companies have developed “real food formulas” containing exactly that: real food blended and pureed to a consistency that can be administered through a gastrostomy tube. As in most nutritional methodologies, there are pros and cons that parents and caregivers should consider prior to adopting a partial or complete blenderized diet for their child.

DR. ANN MARIE DAVISON

Dr. Davison is a faculty member in the biology department at Kwantlen Polytechnic University near Vancouver, BC, Canada where she has been teaching genetics for over 20 years. She has been married to her husband Mark for 19 years. She enjoys traveling and crafting, especially card making.

Presentation: Adult Outcomes Study Update

DR. GREGORY DEAN, MD

Dr. Gregory Dean is a board certified urologist who specializes in pediatric urology. He is a graduate of Oberlin College, and he received his medical degree from Columbia University College of Physicians & Surgeons. Dr. Dean is an Associate Professor of Urology/Pediatrics at Temple University/ Temple Children’s Medical Center. He is affiliated with Shriners Hospital Philadelphia, Abington Memorial Hospital, and St. Christopher’s Hospital for Children. Dr. Dean serves on the Board of Directors of "Healing the Children - Greater Philadelphia" a non-profit that provides access to medical care for children in need all around the world Dr. Dean has been in practice for more than 20 years.

Presentation: Urology and AMC

DR. MAUREEN DONOHOE, PT, DPT, PCS

Dr. Donohoe is a pediatric physical therapist and clinical specialist at Nemours/ Alfred I duPont Hospital for Children where she has specialized in pediatric orthopedics and participates in many of the hospital’s orthopedic specialty clinics. She has been the primary PT in the arthrogryposis program at the hospital since 1989 and the clubfoot program since 2009. Reenee has also spent over 20 years working part time as a preschool and school based physical therapist. Most recently, through her personal contracting agency she has been supplying consultative PT services to adults with pediatric disorders. Dr. Donohoe has authored the chapters on arthrogryposis and osteogenesis imperfecta in all five editions of the textbook Physical Therapy for Children, authored the Relapsed Clubfoot in Pediatric Clinical Case Studies, and the Sports and Recreation chapter in Children with Osteogenesis Imperfecta: Strategies to Enhance Performance. She is actively involved in research involving AMC and has been involved with multiple published research papers. She has had the opportunity to lecture nationally and internationally on AMC.
Presentation: Adult Foot Frustrations. This talk will touch on what has happened since you stopped being seen on a regular basis by a pediatric orthopedist and address strategies to enhance mobility. It will address energy conservation, orthotic considerations, adaptations of shoe gear, and some exercise. The hope is to share some common issues but to also work to answer questions.

Presentation: The Recent Changes in Healthcare Reimbursement: What Are They and How Do They Impact on Care. This will be an overview of some of the changes that went into effect related to physical and occupational therapy as well as some of the changes that are going to be coming for orthotics and adaptive equipment such as wheelchairs. The providers need your help to maximize your benefits.

CAROLINE ELFASSY, MSC. OT (C), ERG.

Caroline is an occupational therapist and research assistant at Shriners Hospital for Children – Canada. As a clinician, she has been actively involved in treating children with AMC and their families. As a research assistant she is currently overseeing a project on rehabilitation practice of youth and young adults with arthrogryposis multiplex congenita. She has recently been accepted to McGill University to pursue her PhD in Rehabilitation Sciences with a focus on AMC.

Presentation: Stakeholders Partnering for Arthrogryposis Research Client-Centered Care in Rehab (SPARC-Rehab): Where are we now? This projects aims to gain a better understanding of the rehabilitation needs as experienced by youth, their caregivers, and clinicians in order to develop guidelines based on the needs identified. This was achieved by conducting semi-structured interviews and coding the information to create the most common themes in each stakeholder group. These themes will allow the research team to gain a richer outlook on the impact of AMC on various aspects of life such as physical needs, environmental and social factors.

Focus group with youth 14-21 years of age. Have you ever seen an occupational therapist or physical therapist? Tell us about your experience and any changes you would like to see. Your feedback will help us develop practice recommendations for rehabilitation.

DR. MICHELLE A. JAMES, MD

As Chief of Orthopaedic Surgery, Shriners Hospital for Children Northern California, Dr. James has cared for children with problems with hand function associated with hand malformations, post-traumatic deformities and neuromuscular conditions for 28 years. She focuses on the child's function and performance, especially from their own perspective. Her research interest is children's hand and arm function, particularly the ability of children with hand problems to perform daily activities and participate in activities of their choice. Her greatest professional joy is learning from a child or their parent that her intervention has improved their ability to accomplish a task that is important to them.

Presentation: The assessment of hand and upper limb function in children with amyoplasia congenita, and potential treatment options for children with this condition. She will review the roles of the occupational therapist and the hand surgeon, and focus on the importance of multi-disciplinary care that takes into account the child’s development and family priorities.
SHERRY MANNING

Sherry Manning is currently the Executive Director of the Nevada Governor’s Council on Developmental Disabilities (NGCDD) after four years as Program Manager and Housing Developmental Specialist for the NGCDD. Prior to accepting the position with the NGCDD, Ms. Manning was the Director of Consumer Credit Affiliates where she provided education and counseling to clients in need of affordable/accessible housing and budget/credit assistance. Ms. Manning’s educational background is in accounting with twelve years as a senior auditor for the State of Nevada Department of Taxation.

Presentation: Sherry Manning, Executive Director of the Nevada Governor’s Council on Developmental Disabilities (NGCDD); will give a presentation on the NGCDD and how it fits into the Developmental Disabilities Act. Ms. Manning will discuss the importance of being an advocate and how that can have impact on systems change at the local, statewide and national level.

DR. SCOTT OISHI, MD

Dr. Scott Oishi is the Director of the Hand Service at Texas Scottish Rite Hospital for Children in Dallas, Texas. He is a Professor in the Department of Plastic Surgery and the Department of Orthopaedic Surgery at the University of Texas-Southwestern Medical School. He provides upper extremity care for many AMC patients and has given lectures on treatment strategies in these patients both Nationally and Internationally.

Presentation: Patients with AMC can have severe limitations in function of their upper extremities which can greatly affect independence. In this presentation, I will discuss our treatment strategy from birth until fully grown. This will include surgical options as well as timing for surgery on the upper extremities. In addition, I will cover aspects of splint use and therapy which are integral in our overall care.

FILIBERTO ONTIVEROS

Filiberto is the father of AMCer Junhyyo and advocate in the disabilities community. He was the Recipient of the 2015 Nevada Family Advocate Award. Past member of the Nevada Governor's Council on Developmental Disabilities and graduate of “Partners in Policy”. He recently began a small business “Ontiveros Affordable Adaptations” making adapted switch toys.

Presentation: “Advocating for Your Child from Within the System.” The presentation is geared towards parents, family and self-advocates. The presentation will touch on being the best representative for your child or self. How to get your story across in order to convey the needs with just enough emotion. Attendants will learn how to get involved in their immediate and broad communities and how to effect changes that are bigger than the needs of our own children with the goal of looking into the future.

Presentation: “The Role of a DAD as a Problem Solver.” In a world where moms are commonly the main care provider, Dads can often feel pushed aside or excluded. What should be our role and how can we become more involved. From team member and friend to problem solver and the final voice. We will discuss if you are a DAD
how to include yourself, if you are not DAD we will discuss ways to give dad a bigger experience and inclusion in the day to day world of our kids.

DR. KARL RATHJEN, MD

Dr. Karl Rathjen is a Pediatric Orthopaedic Surgeon at Texas Scottish Rite Hospital for Children and serves as President of the Hospital’s Foundation. He is an honor graduate of The University of Texas at Austin, and received his medical degree from The University of Texas Southwestern Medical Center at Dallas; where he is now a Professor of Orthopaedic Surgery. In 21 years of practice he has developed an internationally recognized expertise in scoliosis and congenital differences of the hips, knees and feet – conditions on which he has published multiple peer review articles and book chapters and on which he regularly lectures around the world.

Presentation: A multi-disciplinary approach to the management of spine and lower extremity differences in children with arthrogryposis.

RACHEL SCHICKOWSKI

Growing up in the Midwest with AMC makes life interesting. Rachel is proud to say she has mastered crutches and snow (well, most of the time). She graduated with a degree in Journalism and Mass Communication and when she’s not working, Rachel can be found with her two favorite boys, Shane (hubby) and Oliver (son)

Presentation: My leg is not broken...10 things I learned (so far) in my journey as a mom who has AMC. Growing up with AMC, I figured out my way of doing things. When my son was born my journey started again in a whole new (and a little scary) way. Attend this session to takeaway tips and tricks on AMC life with pregnancy and beyond. For more information mylegisnotbroken.com.

BETH SELLERS, MAED

Beth Sellers is a parent of a 10 year old with Arthrogryposis, who also happens to be blind. She also has another daughter with multiple disabilities including cerebral palsy and blindness, and two other kids without disabilities. Beth has spent her career working with students who have unique abilities both as a special education teacher and as an assistive technology specialist.

Presentation: Have you ever wondered if you or your child could benefit from assistive technology at home or at school? Are you uncertain what assistive technology even is? Join us for a brief overview of basic assistive technology solutions with links to resources that you can use to help your child access both homemade and off-the-shelf assistive technology solutions. Both low tech (Velcro and twist-ties) and high tech (Chromebooks and iPads) will be discussed. A question and answer time will be provided at the end. All handouts will be available in digital format.
DR. KIT SONG, MD

Dr. Song is Professor of orthopedic surgery at UCLA Geffen School of Medicine and Medical Director of Surgical Services for the UCLA faculty practice group. He trained at the University of Washington and the Texas Scottish Rite Hospital for Children in Dallas, staying on staff in Dallas for 3 years before returning to Seattle Children’s Hospital where he spent nearly 20 years managing complex pediatric musculoskeletal and spine problems. He served as the orthopedic consultant to the Seattle Children’s arthrogryposis clinic and director of the complex spine and early onset scoliosis program. He has been active in the Pediatric Orthopedic Society of North America, the Scoliosis Research Society, and the American Academy of Orthopedic surgery in the areas of quality, safety, and value in health care. He has a Master’s in Health care administration from the University of Washington and in his current role works within UCLA health to develop strategies for the rational delivery of surgical specialty health care by UCLA to Southern California populations.

Presentation: In my presentation, I will present an approach to the musculoskeletal management of children with amyoplasia. The natural history related to children who receive management, key points to consider in making decisions around care options, anticipated outcomes, and timing and staging of procedures will be discussed. Though the population emphasized will be children with amyoplasia, the principles involved would apply to all children with arthrogrypotic conditions.

JESSI SPRING

Master Gardener working with the Greater Greenville Master Gardener Association. She also runs Southern Roots Farm, a hobby farm in South Carolina. As a mom to a 7-year old AMCer, accessibility is a constant focus.

Presentation: Gardening for Everybody and Gardening for Every Body. With a work smarter not harder approach, gardening can be a job for everyone. Using raised beds, garden tables, containers, etc, anyone can grow flowers and/or their own food. We will discuss gardening basics, soil health, tips to make gardening easier. Additionally, we will go over building techniques, adaptations, tools and tricks-of-the-trade to make jobs easier.

BRIAN C. STONE

Brian is an adult AMCer who is 51 years old. His arthrogryposis impacts all major joints. He’s had 16 surgeries and 6 broken bones. Brian is a Certified Fitness Trainer and the founder of First Step Fitness. He holds a 1st Degree Black Belt in Non Classical Gu Fu and was inducted into the Masters Black Belt "Hall Of Fame" in 2009. He has owned and operated three personal training studio's in the past 17 years. Prior to being a personal trainer, he was an Accountant for 10 years.

Presentation: Brian will share stories about his transformational life journey to inspire and motivate my clients and audiences. His message is that no matter what our personal challenges may be, we can achieve better health, enduring resilience and a winning attitude through a commitment to fitness. He offers practical advice on ways to build fitness despite physical limitations and carry the benefits forward to foster success in other areas of life.
**DR. HAROLD VAN BOSSE, MD**

Dr. van Bosse is on staff at the Shriners Hospital for Children in Philadelphia, where he has had the opportunity to develop a specialty practice in the treatment of children with arthrogryposis. In addition, he enjoys treating the entire realm of pediatric orthopaedic surgical conditions, with special interests in limb deformity, neuromuscular disease, and pediatric spine deformities.

Presentation: “AMC 101 part 1” 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 designed to provide a structure to understand arthrogryposis, in terms of its causes, and differences between diagnoses.

Presentation: “AMC 101 part 2” In this continuation of “AMC 101 part 1”, strategies to address lower extremity deformities will be discussed, including dislocated hips, hip contractures, knee contractures, and foot deformities.

**CONFERENCE MEETING SPACE**
ANNUAL CONFERENCE SESSIONS

AMC SESSIONS
A time for AMCs, parents of AMCs, partners of AMCs and grandparents of AMCs to gather and talk, including but not limited to their fears, dreams, and accomplishments. These sessions are for the specific population mentioned in the session description: Adults (18 and over) with AMC, Young Adults with AMC (18-25), Men with AMC, Women with AMC, Teens and Tweens with AMC, Adult Partners of AMCs, Dads of AMCs, Moms of AMCs, Adoptive Parents of AMCs, and Grandparents of AMCs.

We ask that all others respect the personal nature of each session and only attend the session that applies to you as an individual; respectfully, all others will be asked to leave and directed to the appropriate session.

PAINTING WITH THERESA

FACE PAINTING WITH CHRIS - MAKE YOUR OWN SCARMAN DOLL WITH WARD
Theresa Lucas, an artist with arthrogryposis, has held this painting session annually since our first conference in 2006. This session is fun for all ages, teaches children to embrace their ‘diff-ability’, express themselves through art, and form new friendships with others. www.theresalucas.com

Chris Hartwick, AMCer/Artist also provides “Face painting with Chris” for all ages. www.artistsguildgalleryofgreenville.com

Ward Foley, AKA: Scarman, is a motivational speaker and author of Thank My Lucky Scars. He is providing a session for children with arthrogryposis to draw outlines of their scars to personalize their very own Scarman doll. www.wardfoley.com

SIBLING WORKSHOP
Sib-shop is a place for siblings to unite and share their experiences with arthrogryposis. It provides siblings the opportunity to voice their questions, feelings, and other concerns that may arise in hopes of each child learning from the other.

This session is for AMCer Siblings - 7 years old and older.

Lead by: Sian Foster

ANNUAL PUBLIC MEETING
Open to all AMCSI conference attendees. Come learn what YOUR Board of Directors is doing to follow our mission and vision.

We’re looking for a few good volunteers!

Stop by the registration desk to learn about volunteer opportunities at the conference.

Interested in helping at next year’s event? Email us at bod@amcsupport.org
CHILDRN’S PROGRAMMING

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<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
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<tbody>
<tr>
<td>Thursday June 29, 2017</td>
<td>2 PM to 3:30 PM  Meet, snuggle, and read to the adorable therapy dogs by Love Dogs!</td>
<td>Grand Ballroom D/E</td>
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<tr>
<td>3:30 PM to 5:00 PM</td>
<td>Giant games: Giant tic-tac-toe, giant bowling, sumo bumpers, jumbo playing cards, giant slinky, large ring toss, baseball, scooters, slap bracelet art, decorate thank you cards, and more</td>
<td>Grand Ballroom D/E</td>
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<tr>
<td>Friday June 30, 2017</td>
<td>9 AM to 9:45 AM  Giant Games or Shake Your Sillies Out by Hunter Countryman</td>
<td>Grand Ballroom D/E</td>
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<td>10 AM to 10:45 AM</td>
<td>Giant Games or Shake Your Sillies Out</td>
<td>Grand Ballroom D/E</td>
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<tr>
<td>11 AM to 11:45 AM</td>
<td>Crafts/Ornaments by Linda Garcia and Doodling with Illy Hernandez</td>
<td>Grand Ballroom D/E</td>
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<td>12 PM to 2 PM</td>
<td>Lunch - Children’s Programming Closed</td>
<td>On your own</td>
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<tr>
<td>2 PM to 5 PM</td>
<td>Glow Party: glow sticks, glow beach balls, glow ring toss, glow tic-tac-toe, glow spin tops, glow bracelet making, glow face painting, DIY glow art, magic scratch art, and more!</td>
<td>Grand Ballroom D/E</td>
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<tr>
<td>Saturday July 1, 2017</td>
<td>10 AM to 12 PM  Painting with Theresa, Face Painting with Chris, Scarman Dolls</td>
<td>Grand Ballroom D/E</td>
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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.
- During Painting with Theresa please don’t let children ‘swim’ in the paint or use paint on Scarman dolls. We try to reuse all acceptable, leftover supplies.
- The hotel elevators are for the use of all guests, children are not permitted to “play” on the elevators.
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<tr>
<th>Time</th>
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<tr>
<td>4 PM to 7 PM</td>
<td>Registration</td>
<td>Grand Lobby</td>
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<td>7:15 PM to 10 PM</td>
<td>Welcome Social</td>
<td>Cascade</td>
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<tr>
<td><strong>Wednesday June 28, 2017</strong></td>
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<tr>
<td>4 PM to 5 PM</td>
<td>Registration</td>
<td>Grand Lobby</td>
<td>A</td>
</tr>
<tr>
<td>5 PM to 6 PM</td>
<td>Opening Ceremony with Keynote Speaker Dr. Noémi Dahan-Oliel</td>
<td>Grand Ballroom</td>
<td>A</td>
</tr>
<tr>
<td>6 PM to 8 PM</td>
<td>Lunch</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>8 PM to 10 PM</td>
<td>Lunch</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>11 PM to 12 AM</td>
<td>Lunch</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td><strong>Thursday June 29, 2017</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Registration</td>
<td>Grand Lobby</td>
<td>A</td>
</tr>
<tr>
<td>10 AM to 10:45 AM</td>
<td>Opening Ceremony with Keynote Speaker Dr. Noémi Dahan-Oliel</td>
<td>Grand Ballroom</td>
<td>A</td>
</tr>
<tr>
<td>10:45 AM to 11 AM</td>
<td>AMCSI Annual Meeting</td>
<td>Grand Ballroom</td>
<td>A</td>
</tr>
<tr>
<td>11 AM to 11:20 AM</td>
<td>First Time Attendee Welcome</td>
<td>Grand Ballroom</td>
<td>N</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>12 PM to 3 PM</td>
<td>Registration</td>
<td>Grand Lobby</td>
<td>A</td>
</tr>
<tr>
<td>2 PM to 2:45 PM</td>
<td>Reenée Donohoe: Adult Foot Frustrations</td>
<td>Grand Ballroom A</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Maureen Casey: Understanding your educational rights</td>
<td>Grand Ballroom B</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Dr. Harold van Bosse: AMC 101 Pt 1</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>CoEd Teens and Tweens with AMC</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Families through Adoption</td>
<td>Cataluna A</td>
<td>P</td>
</tr>
<tr>
<td>2 PM to 5 PM</td>
<td>Children’s Programming</td>
<td>Grand Ballroom D/E</td>
<td>C</td>
</tr>
<tr>
<td>3 PM to 3:45 PM</td>
<td>Don Brown: Special Needs Trust</td>
<td>Grand Ballroom A</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Harold van Bosse: AMC 101 Pt 2</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Moms of AMCers: 10 and Under</td>
<td>Grand Ballroom B</td>
<td>P</td>
</tr>
<tr>
<td>3 PM to 4:45 PM</td>
<td>Adults with AMC</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td>4 PM to 4:45 PM</td>
<td>Filiberto Ontiveros: Advocating From Within the System</td>
<td>Grand Ballroom A</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Tricia Catalino: Early Intervention Best Practice</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Moms of AMCers: 11 and Up</td>
<td>Grand Ballroom B</td>
<td>P</td>
</tr>
<tr>
<td>6 PM to 8 PM</td>
<td>Group Dinner</td>
<td>Marquis Ballroom</td>
<td>A</td>
</tr>
</tbody>
</table>

Session Key: A - All Attendees, C - Children’s Activities, M - Medical Focus, N - New Attendees, P - Peer Support: Attendance restricted, S - Skills or Service Focus
<table>
<thead>
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<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Reenee Donohoe: Recent Changes in Healthcare Reimbursement</td>
<td>Grand Ballroom A</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Filiberto Ontiveros: DAD as a Problem Solver</td>
<td>Grand Ballroom B</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Michelle James: Upper Extremities Amyoplasia</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td>9 AM to 10:45 AM</td>
<td>Adult Men with AMC 18 and older</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Adult Women with AMC 18 and older</td>
<td>Cataluna A</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Children’s Programming</td>
<td>Grand Ballroom D/E</td>
<td>C</td>
</tr>
<tr>
<td>10 AM to 10:45 AM</td>
<td>Caroline Elfassy: SPARC Rehab</td>
<td>Grand Ballroom A</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Jessi Spring: Adaptive Gardening</td>
<td>Grand Ballroom B</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Kit Song: Treatment of Amyoplasia in lower extremities</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td>Beth Sellers: Adaptive Technology</td>
<td>Grand Ballroom A</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Brian Stone: Fitness Trainer</td>
<td>Grand Ballroom B</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Gregory Dean: Urology</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Teen/Tween Boys with AMC 10-17</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Teen/Tween Girls with AMC 10-17</td>
<td>Cataluna A</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Children’s Programming</td>
<td>Grand Ballroom D/E</td>
<td>C</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>2 PM to 2:45 PM</td>
<td>Caroline Elfassy &amp; Noémi Dahan-Oliel Clinical Research: 60 minute session</td>
<td>Grand Ballroom A</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Dr. Scott Oishi: Upper extremities</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Grandparents of AMCsers</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td>2 PM to 3:15 PM</td>
<td>Caroline Elfassy &amp; Noémi Dahan-Oliel Clinical Research: 90 minute session</td>
<td>Grand Ballroom B</td>
<td>M</td>
</tr>
<tr>
<td>2 PM to 3:45 PM</td>
<td>Dads of AMCsers</td>
<td>Cataluna A</td>
<td>P</td>
</tr>
<tr>
<td>2 PM to 5 PM</td>
<td>Children’s Programming</td>
<td>Grand Ballroom D/E</td>
<td>C</td>
</tr>
<tr>
<td>3 PM to 3:45 PM</td>
<td>Sherry L. Manning NV. Gov. Council on DD</td>
<td>Grand Ballroom A</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Karl Rathjen: Spine</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Sib Shop Ages 9-17</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td>3:15 PM to 3:45 PM</td>
<td>Ann Marie Davison - Adult Outcomes Update</td>
<td>Grand Ballroom B</td>
<td>M</td>
</tr>
</tbody>
</table>

Session Key: A - All Attendees, C - Children’s Activities, M - Medical Focus, N - New Attendees, P - Peer Support: Attendance restricted, S - Skills or Service Focus
**Friday June 30, 2017**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 PM to 4:45 PM</td>
<td>Rachel Schickowski: My Legs are NOT Broken</td>
<td>Grand Ballroom B</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Christina Crowder: blenderized diets, nutrition</td>
<td>Grand Ballroom C</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>and AMC</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Partners of Adults with AMC</td>
<td>Castilla</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Young Adults with AMC 18-30</td>
<td>Cataluna A</td>
<td>P</td>
</tr>
<tr>
<td>7:15 PM to 10 PM</td>
<td>Talent Show and AMC Dance Party</td>
<td>Grand Ballroom A/B/C</td>
<td>A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Group Photo</td>
<td>Grand Ballroom A/B/C</td>
<td>A</td>
</tr>
<tr>
<td>10 AM to 11:45 AM</td>
<td>Painting with Theresa, Face Painting with Chris,</td>
<td>Grand Ballroom D/E</td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>Scarman Dolls</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2:00 PM to 2:45 PM</td>
<td>Closing Ceremony, Announcement of 2018 Location</td>
<td>Grand Ballroom A/B/C</td>
<td>A</td>
</tr>
</tbody>
</table>

**Session Key:**
- A - All Attendees
- C - Children’s Activities
- M - Medical Focus
- N - New Attendees
- P - Peer Support: Attendance restricted
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**PLEASE REMEMBER**

- ALL children under the age of 14 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 room with your child(ren) during all Children’s Programming.
- 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 keep “Rubber Duckies” out of the fountains.
- Please remember we are able to provide this conference through the generosity of our members and attendees.
- Alcohol is NOT permitted at any conference 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.
- During Painting with Theresa please don’t let children ‘swim’ in the paint or use paint on Scarman dolls. We try to reuse all acceptable, leftover supplies.
- 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.
- The Arthro-pie-posis challenge may NOT take place at the hotel. We know it would be fun, but the staff would not appreciate your mess.
<table>
<thead>
<tr>
<th>Name</th>
<th>Message</th>
</tr>
</thead>
<tbody>
<tr>
<td>#KeiraRocks</td>
<td>I am so proud of you! And #thatsmyMary too!! I love you! Mom</td>
</tr>
<tr>
<td>Gabe Casados</td>
<td>You are an amazing young man and are loved more than you can ever know! We are so proud of you! Love you more than air, air air - Mom, Dad, Tor, Curt</td>
</tr>
<tr>
<td>For Our Awesome Athena</td>
<td>Keep on Reaching Out to Do Everything You Want to Do. You Are AMAZING! Love Grandma &amp; Papa</td>
</tr>
<tr>
<td>Gabby Dangay</td>
<td>You are a brightly shining star in our family. We love you dearly and are very proud to call you our granddaughter.</td>
</tr>
<tr>
<td>To all the AMC moms,</td>
<td>dads, grandparents and caregivers: THANK YOU for all that you do!</td>
</tr>
<tr>
<td>Nathan, Great-Grandmom</td>
<td>Great-Grandmom loves having fun with you at the conference. You are great. I love you. Love, Great-Grandmom</td>
</tr>
<tr>
<td>Dear Ariana</td>
<td>You are a bright shining star that lights up our world! We love you. Mom &amp; Dad</td>
</tr>
<tr>
<td>Inspiration comes in</td>
<td>all shapes and sizes. Thank you Lucas and the amazing Keeline family for the love and inspiration you bring to everyone around you! Love, Lemon</td>
</tr>
<tr>
<td>Never stop reaching</td>
<td>for the Stars Nathan Tighe! You are my inspiration and I love you very much! Suzy xo :-)</td>
</tr>
<tr>
<td>Dear Nathan... keep on</td>
<td>reaching for the stars! You are one awesome boy! Daria</td>
</tr>
<tr>
<td>Best wishes Nathan</td>
<td>Tighe for a wonderful conference. Have a great time. Love Uncle Andy &amp; Aunt Connie</td>
</tr>
<tr>
<td>Nathan:</td>
<td>You are a bright star in this world. Never give up reaching for the moon. The Flyers need you to keep cheering them on. Love, Dianna &amp; Dick</td>
</tr>
</tbody>
</table>
Greetings Nathan Tighe from Aunt Julie & Uncle Clem

William Gephartd, you are our shining star and inspiration! We are so proud of you and all you do! Love, Grams and Pop Pop

Kiely-Ann "Red" we are so proud of how independent and strong you are. You are such a beautiful, smart and funny young lady <3 love you bunches & bunches <3 Mom & Dad

Always reach for the stars PJ!! We love you SO much. - Aunt Cassie, Nana and Gigi!!!

Nathan, You are the sunshine of my life and an inspiration to all who know you. Have fun with your AMC friends. I love you, Aunt Debbie

Nathan, Just to share a bright "hello", sending hugs to let you know "WE LOVE YOU".Flash on.....John Paul, Jillian & Cholly

Nathan: You are our hero. Have a wonderful time. Always reach for the stars. Love, Celeste & Jen

Nathan. The girls of Kolsby Gordon hope you enjoy Las Vegas & the AMC convention. You are amazing! Kit, Tracey, Yari, Rita

Nathan, Micki & Ed: Wishing all of you a wonderful time at the AMC convention in Las Vegas. Love you, Aunt Julie

Dear Nathan: Reach for the stars and follow your dreams. Have Fun. Love, Margie and Donnie

Nathan: Keep on shining!!!!! Love, Andrea P.

Micki & Ed: You are the wind beneath Nathan's wings; the reason he soars with confidence, love and happiness, Love Debbie & John
To Nathan Edward,

We wish we could give you the ability to see yourself through our eyes; Only then would you realize how amazing you are to us.

Love, PopPop and Nanny
Loon Crew:

Thank you once again for the honor of working with you. You are an incredible group of women, and your individual expertise combines to make an amazing team. I could not do this without you, and I don’t want to try! Thank you from the bottom of my heart.

~Michele

AMCSUPPORT.ORG
Arthrogryposis Multiplex Congenita Support, Inc.

Allen, David, Andrew, Christopher and Kaylin,
I am so happy that you are here with me this year.
Thank you for your understanding as I planned for
this year’s conference...even when it meant take-out
for dinner (if you were lucky), sticky-notes on the living
room wall, and my endless hours at the computer.
I love you all very much!

~Michele/Mom

The 2017 Conference Planning Team
and the Board of Directors
of Arthrogryposis Multiplex Congenita Support, Inc.
would like to thank
the Management and Staff
at the
J.W. Marriott Las Vegas Resort & Spa
for their assistance in providing
the 2017 AMCSI Conference.

We would like to extend an extra
"Thank You" to
Bobbi Stirek
Mina Alvarico &
Alex Barcellona
for all of their help.

I would like to thank the
Conference Planning Team,
Current Board of Directors, and all
past members of the
planning team and Board
for their hard work and dedication
over the past 12 years.
Without YOU there would be no Us.

D. A. C. & K:
ALWAYS REMEMBER THAT LIMITATIONS
DO NOT STAND UP TO DETERMINATION.

Sustainable Design for our Children’s Future
Schaffer Architecture

Tanya Baker
Phone: 614-764 0884
Fax: 206-339-6315
TBaker@helmsbriscoe.com

www.HelmsBriscoe.com

HelmsBriscoe was founded in 1992 by
Roger Helms with a very simple premise – by
representing our clients we can create the best
match between the needs of the meeting planner
and the right hotel. Because we work on behalf
of our clients and not as a hotel representative, we
diligently research hotels all over the world to find
the best location and price based on the criteria
you provide.

AMCSI wishes to extend a sincere “Thank You” to
Tanya not only for her continued efforts in locating
hotels and conference space, but also for her support
of AMCSI’s mission and vision. We would not be
able to provide conference without her assistance.
From the very beginning of AMCSupport.org, Theresa Lucas was an integral part of the Organization. She gave her heart, soul, and love to a cause that is very special to her. Theresa gave not only her time and talent to AMCSI, she gave her heart. This year, at the end of her term, Theresa made the difficult decision to step away from AMCSI in an “Official” role. The Board of Directors, Loon Crew and all of her AMCSI friends would like to Thank her for giving her heart to our organization for so many years. We wouldn’t be where we are today if it wasn’t for you. You have definitely left your footprints on our hearts.

The Board of Directors of AMCSI would like to thank Maureen Goede and Carl Oden for all of their help in ensuring the financial health of AMCSI for the future.

Carl G. Oden CPA, INC.
2973 W. State Road 434 • Suite 100
Longwood, FL 32779
EMAIL: codencpa@embarqmail.com
407.682.7772 FAX 407.682.5539

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Scarman is about empowering children and adults alike to see a glimmer of hope in the darkest of places. Especially from within. We all have scars, some you can see and some you can’t. Helping others to feel so-called normal just the way they are. Being proud of themselves, their struggles and every single scar. Spreading a message of hope, courage and self-acceptance while providing support, friendship and unconditional love.

www.ScarmanUSA.com

Thank you to our volunteer photographers, Alicia, Desiree, and Michelle. Thank you for giving so much of your time to capture those special moments that make our Conference feel like a gathering of family.

Many times work that happens behind the scenes goes unnoticed. AMCSI would like to thank Lori Kennedy Carpenter and Ileana Hernandez for their efforts in creating the new website design for AMCSupport.org. It is amazing!

Theresa Lucas
Watercolor Artist
amcreesa@gmail.com
www.theresalucas.com

We’re so proud of you, Gabby! You were a smart, adorable toddler, and now you’re a smart, adorable young lady. We all love you more than you know.

Love, Mom, Dad, Alex, and Julian

Thank you to the Gephardt & Balent Grandparents!
We couldn’t have made it this far without your love and support.
Matt, Jean, William, Jonathan & Edison

The Planning Team would like to thank David Potter from ELITE Audio Visual Solutions for going above and beyond expectations in meeting the Audio Visual needs for this event. We couldn’t have done this without him.

Four Seasons Cuisine
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chef@thefourseasonscuisine.com
www.thefourseasonscuisine.com
Dear Sadie,
You light up our lives!
We love you!
Project Scissor Gait Foundation is dedicated to supporting those who were born with Prune Belly Syndrome and Arthrogryposis or AMC. Our mission is to raise awareness and educate the general public in regards to PBS and AMC as well as finding ways to fund research and provide scholarships for individuals affected with Prune Belly Syndrome and Arthrogryposis.

We are proud to be a sponsor of the Arthrogryposis Multiplex Congenita Support Inc., 12th Annual AMCSI Conference. We hope you enjoy the conference while supporting families and individuals affected with Arthrogryposis and other related conditions.

For more information visit ProjectScissorGait.org

*Project Scissor Gait Foundation is a charitable project of United Charitable, a 501(c)(3) public charity. Your gift is appreciated and tax deductible as a charitable contribution.
THE BOARD OF DIRECTORS

FOUNDER: ANI SAMARGIAN

Ani is the proud wife of Darrell Mahan, and mom of AMCer, Abby, Aiden, Isabella and Ciaran Allen. She serves on the Board of Directors for both AMCSI and South Carolina Disabilities and Special Needs. She is a Support Parent for Family Connection of South Carolina. Learning about Abby’s AMC and supporting families going through similar situations was the inspiration behind amcsupport.org. Ani is a 2015 graduate of the Grassroots Leadership Development Institute and recently completed the Non-Profit Management certificate program at Winthrop University. Ani and her family live in South Carolina.

PRESIDENT: LANA PRATER

Lana Prater was born with Arthrogryposis Multiplex Congenita. Lana has 2 adult children and married her best friend, Delmer, in 2005. Lana was so blessed attending her first conference in 2013 that she knew right away she wanted to be a part of this amazing organization and help raise awareness of this rare condition. Lana volunteered for a nonprofit pet adoption agency and owned and operated her own cleaning company for 7 years. She now enjoys being a homemaker. Lana loves to sing, spend time with her family and make people laugh. Lana and Del reside in Lewiston, Idaho.

VICE-PRESIDENT: CHRIS HARTWICK

Chris Hartwick is an adult with AMC. He works full-time as a graphic designer for Bob Jones University. He is a founding member of the Artists Guild Gallery of Greenville. He is a member with the Association of Mouth and Foot Painting Artists. In his spare time Chris enjoys cooking and karate. He currently resides in South Carolina.

SECRETARY: JOEY BALISTRERI

Joey Balistreri is the proud parent of Liam, an incredible little two-year old born with AMC. Joey is a former public school teacher and instructional coach and holds a Master’s in Public Administration with a focus in non-profit management from the University of North Carolina at Chapel Hill. Joey is excited to step into his role of Secretary on the AMCSI Board of Directors and continue advocating for Liam and others with AMC. In his free time, Joey loves spending time with his family and enjoying the outdoors; he’s also a classically trained violinist and enjoys participating in community orchestras. Joey and his family currently reside in Milwaukee, WI.

MICHELE SCHAFFER: VICE PRESIDENT OF PROGRAMMING

Michele and her husband, Allen, have four children, David, Andrew (AMC), Christopher, and Kaytlin. Michele works as an Intervention Specialist with the New Albany Plain Local School District. Michele joined the Board of Directors in 2006, and she currently serves as the Vice-President of Programming and leads the Conference Planning Team, AKA: The Loon Crew. In her free time, Michele enjoys spending time with her kids, and singing with The Voices of Ohio. Michele and her family reside in Columbus, Ohio.
SOCIAL MEDIA/WEBSITE: ILEANA HERNANDEZ

Ileana Hernandez is a graphic artist born with arthrogryposis who designed the website for Arthrogryposis Multiplex Congenita Support, Inc. She works as a freelance graphic designer in Los Angeles, CA.

MEMBER AT LARGE: DON BAHR

Don was born in Dickinson, North Dakota. Through the years, his treatment for arthrogryposis was provided by several hospitals with the majority of his care provided by Shriners Hospital for Crippled Children, Minneapolis, Minnesota, where he underwent more than 30 operations and many other procedures. He spent over 8 years as an inpatient. Don earned a BA Degree from Brigham Young University, Provo, UT, and an MSW. Degree from the University of Utah. He worked as a social worker in many capacities, ending his career as a psychiatric social worker for the Utah State Prison. In 1985, he was named Utah Handicapped Person of the year. For 32 years, Don was actively involved with Boy Scouts as a scoutmaster or assistant scoutmaster where he received many honors and awards. Don and his wife, Vonda, have eight children, seven living, 30 grandchildren, three great-grandchildren and are awaiting the arrival of three more! In his free time, Don enjoys the world and his farm.

PARLIAMENTARIAN: SARA GRAVER

Sara Gaver is a senior, honors student, at the University of North Florida majoring in Health Administration with a minor in Community Leadership. She has Arthrogryposis, Amyoplasia in all four limbs. She is a sister and Chief Education Officer for the Kappa Alpha Theta fraternity. Sara also plays on the Brooks Power Soccer Team. Sara also holds a job at UNF’s Welcome Center as a tour guide and the Disability Resource Center as an educational aide. In April 2014, Sara was a creator in OneSpark for her non-profit Project CLOSER. Then that October she was chosen to be a speaker in the TEDxJacksonville conference. In 2015, she was crowned Ms. Wheelchair Florida 2015 and competed for Ms. Wheelchair America where she placed 2nd runner up and “best speech.” Sara and her family reside in Osteen, Florida.

TECHNOLOGY STAFF:

JEROEN TEBBENS: TECHNICAL DIRECTOR

Jeroen Tebbens also known as "King J." Jeroen provides invaluable technical support to the Board of Directors. Jeroen resides in IJsselstein, Netherlands with his wife, Lyanne, and son, Daan. Jeroen earned a degree from Polytechnic University (Netherlands) in Internet Communications and Computer Science. He is employed by Dimension Data Netherlands as an Implementation Consultant for Operations Management and Security. Jeroen does not allow his AMC to hold him back; in his spare time, he enjoys riding his motorcycle and swimming competitively with Masters Swimming, Netherlands.

LORI CARPENTER: WEBSITE

Mom to Gavin (Gavin's Toy Box), IT nerd, researcher and advocate for arthrogryposis.
FINANCIAL COMMITTEE

MAUREEN GOEDE

Maureen Goede was born in Chile, and grew up in Chile, Argentina and Ecuador before finally moving to Miami, FL where she attended high school. In 1983 she met her husband Armand and they were married in 1984. They have 5 children, Michelle, Massiel, Reinier, Josy and Ian. After Hurricane Andrew they moved up to Orlando, FL where Maureen received her Bachelor’s Degree in Accounting and then her Master’s Degree in Business Administration. Maureen is the proud grandmother of Sean, Breanna and Alayna who also live in Florida and 4 others who live out of the country. Sean was born with AMC, and when looking for answers about AMC they found AMC Support. Maureen, Josy and Sean attended their first AMC Convention in Chicago and have been active supporters of AMCSI ever since.

MEDICAL ADVISORY BOARD

BOARD DIRECTOR: DR. HAROLD VAN BOSSE

Dr. van Bosse is on staff at the Shriners Hospital for Children in Philadelphia, where he has had the opportunity to develop a specialty practice in the treatment of children with arthrogryposis. In addition, he enjoys treating the entire realm of pediatric orthopaedic surgical conditions, with special interests in limb deformity, neuromuscular disease, and pediatric spine deformities.

REENEE DONOHOE, PT, DPT, PCS

Reenee is a clinical specialist in pediatric physical therapist at Nemours/ Alfred I DuPont Hospital for Children in Wilmington, DE. She has been actively involved in the AMC clinic since the late 1980’s. In addition she has written textbook chapters for physical therapists on arthrogryposis (Physical Therapy for Children) and on relapsing clubfeet (Physical Therapy Case Files: Pediatrics). Over the years she has been involved in multiple research activities around contracture syndromes. When she is not working at the hospital, she also owns a private practice that provides educationally based physical therapy to children who have physical limitations which impact on their educational process.

DR. JUDITH HALL

Dr. 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. Dr. Hall is also the coauthor of the AMC Text Atlas.
CONFERENCE PLANNING COMMITTEE

MICHELE SCHAFFER: VICE PRESIDENT OF PROGRAMMING

ANI SAMARGIAN: FOUNDER

JEAN M BALENT-GEPhAR: DIRECTOR OF OPERATIONS

Jean, wife to Matt, and mother to William (AMC) and Jonathan, currently lives in Maryland. Jean is an environmental engineer and currently works for the Federal Government. After William’s birth, the Gephardts were overjoyed to find and join the AMCSI community and have been regular attendees at the AMCSI conferences since 2012. She enjoys yoga and volunteering with local environmental cleanup groups in the Baltimore area.

BETSY GATES-EHLERS: DIRECTOR OF LOGISTICS

Betsy is mom to AMCer Jake, and Karl and wife to Andrea. Betsy is a data manager at the University of Illinois at Chicago and is working on a degree in Library and Information Science at the University of Illinois - Urbana-Champaign. In her free time, Betsy plays on the Chicago Frozen Snappers, a recreational women’s ice hockey team and loves to spend summer weekends camping with family. She lives in the town she grew up in just Northwest of Chicago.

LASHELL PAGE: DIRECTOR OF CHILDREN’S PROGRAMMING

LaShell Page is a seasoned 1st grade teacher in Oklahoma and mother of a 4 year old AMCer named Brian and a 2 year old named Cohen. LaShell is married to Robert Page. LaShell graduated from Northeastern State University with a Bachelor Degree in Education. This will be LaShell’s second year as the Children’s Programming Director for the Conference. Making the Conference fun and entertaining for the kiddos is her number 1 priority. LaShell is driven by her love and passion for teaching children in her career, life, and at the conference.

PHOTOGRAPHY TEAM

Alicia McCavanagh
Michelle Mockeridge
NEW OR RENEWED MEMBERSHIP BENEFITS

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

• Discount on registration fees to the annual AMCSI yearly conference
• Access to AMCSI’s annual public meetings and monthly Board of Directors meeting minutes
• AMCSI 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 regional mini meet up grants (grant program currently in development)

www.amcsupport.org/becomeamember
Each of our conference attendees reside in a region. We hope that this is helpful in identifying members close to you! Please take the time to get to know those in your region so that you can begin building a support network close to home.

- Region 1: Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Virginia, West Virginia
- Region 2: Florida, South Carolina
- Region 3: Indiana, Kentucky, Michigan, Ohio, Tennessee
- Region 4: Illinois, Iowa, Minnesota, Nebraska, South Dakota, Wisconsin
- Region 5: Arkansas, Kansas, Missouri
- Region 6: Alabama, Louisiana, Mississippi, Texas
- Region 7: Idaho, Montana, Washington
- Region 8: Arizona, California
- International: Australia, Brazil, Canada, Columbia, Denmark, Finland, Peru, Russia, United Kingdom

Mini Meet-ups take place across each of the regions throughout the year.
Visit amcsupport.org/minimeetups.html to look for a mini meet-up near you!
Throughout the years, we have walked side by side, rejoiced, counseled, and wept beside those in our AMC Family who have lost a loved one with arthrogryposis. We offer our thoughts and love to these families and continue to keep them and their loved ones alive in our hearts and in the spirit of our organization.

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

Payton Leigh Biddy
Jeanne Bozenhard
Claire Cocklin
Jake Charles Cohen
Zaya Lynn Crofut
Diana
Henry Dobrovits
Andrea Nicole “Nickie” Dolan
Klara Handke
Kali Pauline Heglmeier
Ian Hixson
Laughton Joseph
Savannah Nicole Lehl
Rain Maia
Rylee Gene Mann
Alannah Nicole Marshall
Patrick William Martin
Nicholas John Martin
Jameson McCormick
Kendale John McCormick
Caleb Michael
Olivia Mockeridge
E’zra Nelson
Jared Orner
Alexis Irellyn Pendak
Karrington Riley Reynolds
Caitlyn Rose Rout-Langdale
Cynthia Ann Sneddon
Lua March Souza
Arthur Swales
Leah Catherine Tamash
Maxwell Samuel Benvie Taylor
Sarah Rose Tricarico
Gabriella “Ella” Lee Tucker
Zander Christian Young
The third child to Emma and Eugene Pepe, Valerie was deformed at birth, the joints in her lower body out of their sockets. The rare condition was called AMC (Arthrogryposis Multiplex Congenita) and many doctors had never seen anyone who had it. Her parents and extended Italian-American family mobilized. Valerie would have the best medical care and as normal a life as possible. Her life has been more than normal, it has been remarkable. In her strong, down-to-earth voice, Valerie tells a life-affirming story of achievement, love, medical challenge, spunk, personal emancipation, and devotion to helping others afflicted with AMC.

These days Valerie Pepe commutes to her job as an Associate Staff Analyst for the New York City Housing Authority from Staten Island where she still lives in her childhood neighborhood. She does her needlepoint on the long Access A Ride, reads, writes in her journal or calls her new boyfriend in Mississippi. She hosted the internet radio program, “The Val and Betty Show” from 2010-2012 and is the Chairwoman of the AMC (Arthrogryposis Multiplex Congenita) Music Festival which raises funds and awareness about her disability. Her essays have appeared in Woman’s World, DStripped Magazines, Snug Harbor and The Staten Island Advance. She has a BA in English from St. John’s University, an MS in Education from St. John’s University, and a Certificate in Creative Writing from New York University. She is featured in a documentary, “The Sweetest Gift: Living with Arthrogryposis Multiplex Congenita,” a film by Margaret Chaidez.

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Contact Valerie directly for personal appearances and book signings.

valeriepepemusicfestival@gmail.com

917 612-3926
My name is Bob Norris, I started my shop based on an overwhelming interest after crafting two pairs of braces (AFO & KAFO) for a friend’s two daughters. Next thing I knew, I had many requests to make more. It feels good to know that this little project can have a positive impact in a child’s life.

Where to find me?
Etsy.com/shop/ShishkaBobDesign
Facebook.com/ShishkaBobDesign
Instagram- @ShishkaBDesign
Email- Bob@ShishkaBobDesign.net

Each brace is hand-crafted (by me), not in a toy factory, and each one is unique. I believe that these “toy-like-me” items help children feel better about themselves. I also hope it sparks desperately needed conversations about disabilities and the lack of toys that reflect them.