AMCSI IS PROUD TO PRESENT...

Columbus Ohio

#AMCOhio18

13th Annual Arthrogryposis Multiplex Congenita Support Conference
July 4-7 · 2018
Columbus, Ohio
Helping children with arthrogryposis maximize their independence.

Ranked among the very best in the nation for pediatric orthopedics by U.S. News & World Report, Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE, is dedicated to improving the quality of life for children with arthrogryposis.

Our multidisciplinary team provides expert care using bracing, therapy services and surgery to help children reach their full potential.

L. Reid Nichols, MD
Lower Extremity Specialist

Jennifer Ty, MD
Hand and Upper Extremity Specialist

Reenee Donohoe, PT, DPT, PCS
Physical Therapist

Charlie Cercola, OTR/L, CHT
Occupational Therapist/Certified Hand Therapist

Chris Church, MS, PT
Gait and Motion Analysis Laboratory

Tariq Rahman, PhD
Pediatric Engineering Research Lab

Learn more at Nemours.org.
A NOTE FROM OUR FOUNDER

Dear AMC Family,

It gives me great pleasure to welcome you all to Columbus, Ohio, for the 13th Annual AMCSI Conference. The next three and half days will be full of great information, networking and support. Our schedule is filled with many wonderful presentations, support sessions and activities for your children to enjoy.

I would also 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 the 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 Columbus, Ohio. I am excited to meet all of our new AMC families and look forward to all of us having an amazing conference together.

Sincerely,

Ani Samargian,
Founder Arthrogryposis Multiplex Congenita Support, Inc.
A NOTE FROM THE 2018 CONFERENCE PLANNING COMMITTEE

Dear Friends,

The 2018 Conference Committee would like to welcome you to the 13th Annual Arthrogryposis Multiplex Congenita Support, Inc. Conference in Columbus, Ohio! 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. If you are feeling “alone in a crowd” or torn between session options, please seek out a member of the Planning Team or a Member of the Board of Directors for some compassionate advice. We were all first timers once ourselves! We've been told our conference has a “unique” atmosphere, and we take that as a compliment. We want you to feel like a part of our AMC Family.

We would like to extend our thanks to all who have offered to share their time as a volunteer. We could not offer the programming that we do without their 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 will have the opportunity to participate in a diverse schedule designed 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. Some of our speakers are on very tight timelines and may need to leave quickly in order to complete their travel. 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, but 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,

The 2018 Planning Committee

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

LaShell Page,      Beth Sellers     Ani Samargian,
Director of Children’s Programming            Director of Volunteer Services       Founder


A NOTE FROM OUR PRESIDENT

Welcome to the 13th Annual Arthrogryposis Multiplex Congenita Support, Inc. Conference. The planning team has a fantastic few days ready for you. Some of this year’s special events are the Reach for the Stars prom on Friday evening, painting with Theresa and face painting with Chris. I’m especially excited that Dr. Hall is joining us this year to celebrate the 20th Anniversary of Arthrogryposis: a Text Atlas.

It’s an exciting time as AMCSI continues to grow. Misha Walker has joined our team as our very first International Ambassador. Misha is doing some amazing things. Mark Indreika has accepted the role as editor and has appointed a team of proofers. In May, we sent out our first edition of AMC Today which is our newsletter. Look for our second edition in July. There are many more committees on the horizon that will need leaders and support teams. We’ll be looking for hard-working volunteers so watch for those call-outs and be sure to sign up to receive AMC Today at amcsupport.org.

The board of directors has finalized the adoption grant, research grant, and has begun distributing funds for our bereavement and research grants. Our scholarship and adoption grants can now be found on our website. It is through the generous donations of people like you that make these grants possible.

A big thank you goes out to all who have donated to and volunteered for the Ohio 2018 Arthrogryposis Multiplex Congenita Support, Inc. Conference. We could not do it without you.

Thank you for your support,

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

JUDITH G. HALL, MD

Dr. Judith G. Hall is a Clinical Geneticist and Pediatrician. She trained at Wellesley College, the University of Washington School of Medicine and Johns Hopkins Hospital. She was chair of Pediatrics at UBC and BC Children’s Hospital from 1990-2000. She is presently Professor Emerita of Pediatrics and Medical Genetics at the University of British Columbia based at Children’s & Women’s Health Centre of British Columbia in Vancouver, B.C., Canada. Her areas of research interest are human congenital anomalies, natural history of genetic disorders, and non-traditional mechanisms of genetic disease.

Keynote Presentation: Arthrogryposis a Text Atlas: 20 Years Later

Additional Presentation: What’s New in the Genetics of Arthrogryposis - More than 400 different specific syndromes have been described to be born with multiple congenital contractures, and thus fit into the category of “arthrogryposis.” At last count, 330 genes have been found to have mutations that lead to decreased movement in utero. We know that anything that leads to decreased movement in utero can lead to joint contractures at that time of birth. Now, efforts are being made to fit those genes that have mutations into pathways so that we can understand what processes lead to decreased movement in utero.

LYNN T. STAHELI, MD

Dr. Lynn T. Staheli, M.D. trained at Brigham Young University, University of Utah, and the University of Washington. He served in the United States Air Force from 1961–1963. Dr. Staheli has published 85 peer-reviewed research studies and published 16 books, and is also the Founding Editor and Editor Emeritus of the Journal of Pediatric Orthopaedics. In 1998, he edited and published Arthrogryposis-A Text Atlas with Dr. Judith Hall, Dr. Kenneth Jaffe, and Diane Paholke. After his retirement from clinical practice, he focused on promoting the use of electronic publishing in making health care information more widely available and affordable. He founded Global HELP and currently serves as Executive Director for Global HELP.

Keynote Presentation: Arthrogryposis a Text Atlas: 20 years Later - Dr. Staheli will be joining us through a pre-recorded video presentation during the opening plenary.

Arthrogryposis: A Text Atlas, by Lynn Staheli, Judith G. Hall, Kenneth M. Jaffe, and Diane O. Paholke 185 pages, 8.5” x 11”, Four-Color, English, 2008
Devin Aumend is a Senior Vocational Rehabilitation Counselor with Opportunities for Ohioans with Disabilities. For the past six years, she has worked with adults with disabilities in Franklin County to provide vocational rehabilitation services. In addition to coordinating vocational rehabilitation services, she also assists in training new counselors hired at Opportunities for Ohioans with Disabilities (OOD) and mentors new counselors. Devin holds a master’s degree in Community Counseling from Wright State University and is a Licensed Professional Counselor.

**Presentation: A General Overview of OOD Services and Vocational Rehabilitation** – Although this session will focus on Ohioans, it will provide information that is applicable to most states. All attendees are invited to join the session. (Joint Presentation with Kimberly Chaffin).

Don has been in the financial services industry for the past 32 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 on-year volunteer with Camp Fatima of New Jersey, an all-volunteer one-on-one camp for developmentally challenged children. Don is also a member of their volunteer finance committee. 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. In addition, Don is a selected member of the Academy of Special Needs Planners and has been awarded the 5-star Wealth Management Award in New Jersey, a recognition given to only 5% of Financial and Wealth Management Advisors.

**Presentation: Ten Steps for Caretakers of Dependents with Special Needs** - 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 and Medicaid, creating and funding special needs trusts, and the importance of a will and proper estate planning coordination. Taking steps now can help a loved one’s lifetime of care and quality of life!

Kimberly is a licensed Professional Counselor and Rehabilitation Teacher at the Bureau of Services for the Visually Impaired with the Ohio Rehabilitation Services Commission. In her current position she provides vocational counseling and training with low vision devices to blind and visually impaired adults and transition students seeking competitive employment. She has a B.S. from Miami University and M.Ed. from Ohio University.

**Presentation: A General Overview of OOD Services and Vocational Rehabilitation**-Although this session will focus on Ohioans, it will provide
information that is applicable to most states. All attendees are invited to join the session. (Joint Presentation with Devin Aumend).

Suzanne Cherry, PT, DPT, PCS

Suzanne Cherry, PT, DPT, PCS, is the Director of Rehabilitation at Shriners Hospital for Children- Greenville. She has over 27 years of pediatric experience since completing her graduate degrees. Dr. Cherry’s interests include helping a child and family with function and performance in order to maximize participation within their community. She has previously lectured on topics including AMC, Pediatric Outcome Measures, and Physical Activity Interventions in Children with Disabilities. She is both NDT trained and C1 certified in the 3-D Treatment of Scoliosis by the Barcelona Scoliosis Physical Therapy School.

Presentation: Interdisciplinary Approach to treating AMC: Different Perspectives and Ideas

- The multiple disciplines available to care for the child with AMC are as diverse as the diagnosis itself. All contributors (MD, orthotist, therapist, nutritionist, etc.) have a unique role with different perspectives and ideas. When working with the caregivers and the child, these team members can assist and support in setting realistic goals, and establishing a “plan of care” to best serve the individual with AMC. Communication aids understanding of the need for intensive therapy, surgeries, and orthotic requirements. A partnership between the multiple disciplines allows focus on the different needs of each child’s developmental stage. With collaborative care, children with AMC can fully maximize their potential, meeting the high expectations we know they can all achieve. (Joint presentation with Dr. Lisa Wagner).

Noémi Dahan-Oliel, PhD

Noémi Dahan-Oliel, Ph.D. is a Clinician Scientist and Coordinator of the Clinical Research Department at Shriners Hospital for Children in Montreal, Canada, and an Assistant Professor in the Faculty of Medicine, School of Physical and Occupational Therapy at McGill University. She earned a doctoral degree in Rehabilitation Science from McGill University in 2014. Noémi recently completed a Professional Certificate in Knowledge Translation from the Hospital for Sick Kids and University of Toronto. Her research program is focused on improving the clinical interventions of children with arthrogryposis using a collaborative approach. By engaging youth with AMC, families, and clinicians in research, research priorities that are relevant to key stakeholders can be identified, thus leading to meaningful studies, which can be shared and integrated into practice. When not at work, you can find Noémi making pancakes with her 5-year old son, trying to help her older kids with homework, or walking her dog Chips.

Presentation: Research in arthrogryposis: Current and New projects for children and youth.

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 van Bosse. 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.
MAUREEN DONOHOE, PT, DPT, PCS

Reenee 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 the over 20 years working part time as a preschool and school based physical therapist. 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: Movement is Exercise** - This talk will discuss ways to encourage activity and fitness despite physical limitations. It is a lecture not just geared towards enhancing activity for children but also through adulthood. Will highlight activities that can be performed by those with a wide variety of physical abilities. Emphasis on participation and ability to track exercise. Please come and be prepared to share some of your strategies for exercise.

DAVID S. FELDMAN, MD

Dr. David S. Feldman, MD is an internationally recognized, American Board Certified, orthopedic surgeon who stands at the forefront of complex pediatric and adult orthopedic procedures and treatments. He is currently the Director of Spinal Deformity and Hip Preservation Centers at the world-renowned Paley Institute in Florida. An expert in the care of spinal deformities such as scoliosis and kyphosis and specializes in treating patients with complex conditions such as arthrogryposis, achondroplasia, MHE, hip dysplasia, Legg-Calve-Perthes Disease, lower limb deformities and limb length problems.

**Presentation: New Developments in Lower Extremity Surgery in Arthrogryposis and the Future of Upper Extremity Management** - A discussion regarding increasing motion in the hip and knee, fixator-free, and thereby improving ambulation. A classification that helps in regard to decision making in lower extremity arthrogryposis hip and knee contractions. Finally, a futuristic discussion of possibilities of regaining motion and function in the upper extremity.

CAITLYN FULTON

Caitlyn Fulton graduated from the University of New Hampshire with a BA in economics in 2014, and recently returned to UNH to study mathematics, with the goal of becoming a high school math teacher. Born with AMC, she has become a voice for her students with disabilities at UNH, including starting a club on campus, UNH Access4All. She credits her work as a lab assistant for Therese Willkomm in the Assistive Technology Lab at the UNH Institute of Disability, along with a course called Disability Justice, for her inspiration to make the world a more welcoming place for people with disabilities and chronic illness.
Presentation: Creating Assistive Technology Solutions in Minutes for Individuals who Experience Arthrogryposis - This workshop will discuss and demonstrate over 50 different solutions that have been created to accommodate individuals who experience arthrogryposis. Examples include: hands-free devices for eating, drinking, self-care; workplace accommodation solutions for turning lights on, transporting objects; Cutting paper, turning pages, writing, and teaching; access solutions for typing on a cell phone; and multi-use holding and grasping solutions. (Joint Presentation with Therese Willkomm, PhD)

PHILIP F. GIAMPIETRO, MD, PHD

Philip F. Giampietro, MD, PhD, is a professor in the Department of Pediatrics at Drexel University College 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, residency in Pediatrics at Long Island Jewish Medical Center and 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. Dr. Giampietro is Chief of the Section of Medical Genetics at St. Christopher’s Hospital for Children. Prior to his current position, Dr. Giampietro held positions at the University of Wisconsin-Madison, 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.

Presentation: What is a Genetic Evaluation and How Will This Benefit My Child and Family? - Arthrogryposis has many different subtypes which have different individual causes, and natural histories. There are often misconceptions as to how arthrogryposis may have occurred and a desire for families to know what the chances are for having another affected child. In this lecture, we will discuss the benefits of a genetic evaluation and outline the different types of genetic tests which are commercially available for arthrogryposis. An outline of the components of a genetic evaluation will be presented. We will summarize the genetic counseling process which helps to provide families with a better understanding of their child's condition.

CLAIRE Z. KALPAKJIAN, PHD, MS

Dr. Claire Z. Kalpakjian, PhD, MS, is an Associate Professor in the Department of Physical Medicine & Rehabilitation at the University of Michigan. She is a Clinical Psychologist with specialized training in Rehabilitation Psychology and post-graduate training in clinical research. Dr. Kalpakjian has been on faculty at the University of Michigan since 2004 and her program of research centers on disability and rehabilitation, with a dual focus on women's health and psychological outcomes. She has received federal and foundation funding for her research and serves as co-investigator on several other large, federally funded projects in rehabilitation. She has published over 50 peer-reviewed journal articles and three book chapters, presented at numerous national conferences, and serves on several national committees.

Presentation: Women's Health & Disability Focus Group - A team from the University of Michigan has been working with collaborators around the country to create a new survey tool for researchers and
clinicians to use to better understand the experience of women with disabilities. This information can be used when talking with doctors to improve communication and understanding and by researchers to improve health care. This focus group will be an opportunity for women 18-50 years old to give their feedback to researchers on survey's the topics and if anything important is missing. (Joint Presentation with Rebecca Parten).

GAREY NORITZ, MD

Dr. Garey Noritz is an Internist and Pediatrician at Nationwide Children's Hospital and Associate Professor of Pediatrics at The Ohio State University. He is medical director of the Complex Care Clinic and the Comprehensive Cerebral Palsy Program. Dr. Noritz graduated from Brown University School of Medicine. He is Board Certified in Internal Medicine, Pediatrics, Neurodevelopmental Disabilities, and Hospice/ Palliative Medicine. He is on the Executive Committee of the Council on Children with Disabilities of the American Academy of Pediatrics, and is past Chair of the Lifespan Committee of the American Academy for Cerebral Palsy and Developmental Medicine.

Presentation: Understanding Pain and Pain Management in Arthrogryposis - This session will discuss common causes for pain in people with Arthrogryposis, and review various treatment modalities.

NATASHA O’MALLEY, MD

Dr. Natasha O'Malley practices in all areas of Pediatric Orthopaedics and Pediatric musculoskeletal trauma. Her specialist interests include congenital and developmental deformities such as clubfoot, arthrogryposis and limb length discrepancies, as well as care of the injured child. Dr. O’Malley earned her medical degree from University College Dublin in Ireland and completed her surgical and specialist Orthopaedic training there, earning a Fellowship of the Royal College of Surgeons in Ireland in Trauma and Orthopaedics. Following her residency, she completed a Fellowship in Pediatric Orthopaedics at Rainbow Babies and Children’s Hospital in Cleveland, Ohio and is now an Assistant Professor of Orthopaedics at the University of Rochester Medical Center and operates on patients in the new Golisano Children’s Hospital, Rochester.

Presentation: Management Goals and Treatment Options for Knee Issues in Arthrogryposis Multiplex Congenita - The knee is a complex joint, facilitating both movement and rest by its positioning and actions. When function is limited by a congenital condition, a child’s ability to walk and sit are altered and compromised. Arthrogryposis multiplex congenita (AMC) affects the knees at every anatomical layer – the overlying skin, the muscles and tendons underneath, the capsule and bones within the joint. This presentation will discuss normal anatomy and function of the knee, how AMC affects it, and treatment strategies to optimize range of motion and function.
ROBERT PAGE

Robert Page is the father of a 5-year-old AMCer, Brian, and 3-year-old Cohen. Robert has a Bachelor’s Degree in Fire and Emergency Services from Northeastern State University and Paramedic certification from the Cherokee Nation. He is currently employed by the Tulsa Fire Department and St. Francis South Hospital. Robert, his wife LaShell, and the boys currently reside in Tulsa, Oklahoma. This will be the second time for Robert to speak at an AMC Conference.

**Presentation: DIY with PVC** - Robert will be speaking on homemade medical equipment with an emphasis on PVC pipe. The cost of medical equipment is often preventative for most families to provide the tools necessary for an AMCer to succeed. Fortunately, a large amount of that equipment can be made for 1/1000 of the price with little to no technical skills. Robert will be providing guidance, blueprints, ideas, and open discussion on making your own PVC pipe walkers, standers, desks, pump holders, and other various tools.

REBECCA PARTEN, MSW

Rebecca Parten, MSW is a Research Area Specialist in the Department of Physical Medicine & Rehabilitation at the University of Michigan and is in the process of become a fully licensed Macro Social Worker. She conducts recruitment, enrollment and data collection activities for Dr. Claire Kalpakjian’s federally funded projects focused on women’s health and disability. Ms. Parten has expertise in outreach and engagement of community organizations serving people with disabilities to take part in research. Born with Escobar Syndrome, a form of Arthrogryposis, she brings a unique perspective to these projects drawing from both personal experiences as well as her academic and professional experiences.

**Presentation: Women’s Health & Disability Focus Group** - A team from the University of Michigan has been working with collaborators around the country to create a new survey tool for researchers and clinicians to use to better understand the experience of women with disabilities. This information can be used when talking with doctors to improve communication and understanding and by researchers to improve health care. This focus group will be an opportunity for women 18-50 years old to give their feedback to researchers on survey’s the topics and if anything important is missing. (Joint presentation with Dr. Claire Z. Kalpakjian).

BECKY PRINCE

Becky Prince has been working in the field of therapeutic recreation for 20 years. She is employed at Western DuPage Special Recreation Association in the Chicagoland area and provides recreational opportunities for individuals with disabilities. Becky is also the Executive Director of USA Boccia, which is the governing body for the Paralympic sport of Boccia.

**Presentation: Come Learn the Sport of Boccia in an Interactive Demo** - Come and learn about the Paralympic Sport of Boccia! Boccia can be played by anyone, with or without a disability. Originally designed for people with severe cerebral palsy, it is now enjoyed by players with a wide variety of disabilities. It’s easy for a beginner to pick up quickly, but builds in intensity and complexity as players hone their skills. Boccia is a co-ed sport of control and accuracy, similar to curling or lawn bowling. Games last four or six ends. Players propel balls towards the target or “jack” ball. Each side has six balls (red or blue) per end to
try and score points. The closest side to the target ball when all the balls have been played, scores. Can’t throw? No problem. Balls can be rolled or kicked. If a player can’t roll or kick, they can use a ramp. If they can’t let the ball go with their hand, they can use a head or hand pointer. Join us for this interactive demonstration of the sport and find out ways to get involved today!

**Naimisha Shah-Hoffman, DDS**

Dr. Hoffman has spent the entirety of her professional career of over 15 years practicing dentistry in Dublin, OH, where she lives with her husband Jason, son Ashdin (AMCer age 8), and Malini (age 2). She graduated from The Ohio State University with her Doctorate of Dental Surgery in 2003 and completed a General Practice Residency at Miami Valley Hospital where she earned a license in conscious sedation. As a pioneer in Complete Health Dentistry, Dr. Hoffman also practices Family Dentistry and Cosmetic Dentistry. Committed to advancing developments in specialty areas of Dentistry, Dr. Hoffman aspires to educate herself on the challenging dental needs of those affected by AMC, and to give back to this wonderful community.

*Presentation: Ways to Achieve Dental Health and Function in the World of Arthrogryposis* - Dr. Hoffman’s presentation will include basic dental information, ideas, modifications and recommendations for those with arthrogryposis to practically incorporate into their daily routines. There will also be an interactive discussion on dentally related problems experienced by the AMC community, to help guide more targeted research into resources and treatment options.

**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.

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

**Lisa Wagner, DHS, OTR/L**

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-Greenville for the past 27 years has allowed Lisa to participate in various research projects resulting in peer-reviewed 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 the North American clinical instructor for the Assisting Hand
Assessment. Passionate about children with AMC, she is currently collaborating on an outcome assessment for better understanding the upper extremities.

**Presentation: Interdisciplinary Approach to treating AMC: Different perspectives and ideas** - The multiple disciplines available to care for the child with AMC are as diverse as the diagnosis itself. All contributors (MD, orthotist, therapist, nutritionist, etc.) have a unique role with different perspectives and ideas. When working with the caregivers and the child, these team members can assist and support in setting realistic goals, and establishing a "plan of care" to best serve the individual with AMC. Communication aids understanding of the need for intensive therapy, surgeries, and orthotic requirements. A partnership between the multiple disciplines allows focus on the different needs of each child’s developmental stage. With collaborative care, children with AMC can fully maximize their potential, meeting the high expectations we know they can all achieve. (Joint presentation with Dr. Suzanne Cherry).

**Misha Walker**

Misha “Dream” Walker is a Peruvian inspirational speaker and blogger, and the newly appointed AMCSI international ambassador Misha currently lives in Lima, Peru with her husband, Michael. Misha travels the world trying to raise awareness for “arthrogry’what’sis” and visits as many families as she can from our incredible AMC community.” Oh, and she was also born 1 in 3000 AMC Awesome.

**Presentation: Limitless** - From the moment we’re born the world starts creating limits for us. Little boys play with cars, little girls play with dolls, she’s never going to walk, he’s never going to play a sport. Join me for an hour while I try to explain in my own way why all of this is nonsense. If we shut out the noise, ignore those who say that we can’t and follow our hearts, then actually we find that our lives are limitless.

**Kent Williams, MD**

Kent Williams, MD, is an attending pediatric gastroenterologist at Nationwide Children's and the Medical Director of Endoscopy. He is also an Assistant Professor of Clinical Pediatrics at The Ohio State University College of Medicine. Dr. Williams’ clinical interests involve all aspects of pediatric gastroenterology, with a special interest in GI disorders in children. As an investigator at the Research Institute at Nationwide Children's and OSU, he conducts basic and translational research into the mechanisms that cause functional gastrointestinal disorders, such as abdominal pain, constipation, and reflux in children.

**Presentation: Discussion of Gastrointestinal and Nutritional Issues** - Interactive session on Gastrointestinal and Nutritional Disorders with a GI specialist who specializes in treating children with developmental and congenital disorders. Dr. Williams will present a brief overview of evaluation and treatment of common GI disorders in children with developmental and congenital disorders while answering questions from the audience.
**THERESE WILLKOMM, PhD, ATP**

Dr. Therese Willkomm, PhD, ATP, is an amazing Assistive Technology magician who has invented over 1,200 different Assistive Technology solutions including 50 different iPad solutions for people with disabilities. She is known nationally and internationally for her unique five-minute approach to creating solutions using 10 basic hand tools and 30 different every day materials. She has presented in 47 states and eight foreign countries. Dr. Willkomm has authored 22 publications including “Assistive Technology Solutions in Minutes - Make a Difference Today” and “Assistive Technology Solutions in Minutes- Book 2 – Ordinary Items Extraordinary Solutions”. Dr. Willkomm holds a PhD in Rehabilitation Science and Technology and is the director of New Hampshire’s state wide Assistive Technology program. She is also a clinical associate professor in the Department of Occupational Therapy at the University of New Hampshire and oversees the graduate certificate program in assistive technology at UNH.

**Presentation: Creating Assistive Technology Solutions in Minutes for Individuals who Experience Arthrogryposis** - This workshop will discuss and demonstrate over 50 different solutions that have been created to accommodate individuals who experience arthrogryposis. Examples include: hands-free devices for eating, drinking, self-care; workplace accommodation solutions for turning lights on, transporting objects; Cutting paper, turning pages, writing, and teaching; access solutions for typing on a cell phone; and Multi use holding and grasping solutions. (Joint Presentation with Caitlyn Fulton)

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**PEER SUPPORT SESSIONS**

- Adults with AMC: Moderated by Lana Prater
- Adoption: Moderated by Doug and Tracy Hoffman
- Amputation, A parent’s perspective: Moderated by Chaney Roko
- Dads of AMCers: Moderated by Robert Page
- Grandparents: Moderated by Lois Ann Balent & Karen Gephardt
- Men with AMC: Moderated by Mark Indrenka
- Moms of AMCers 11 and older: Moderated by Linda Garcia
- Moms of AMCers 10 and under: Moderated by Alexis Record and Jessi Spring
- SibShop: Moderated by Sian Foster
- Significant Others of AMCers: Moderated by Vonda Bahr
- Teens and Tweens (Not Gender Specific): Moderated by Tracey Schalk and John Jagroop
- Teens and Tweens with AMC-Boys: Moderated by Scott Braddock
- Teens and Tweens with AMC-Girls: Moderated by Theresa Lucas
- Tube Feeding: Moderated by Beth Sellers
- Women with AMC: Moderated by Theresa Lucas
- Young Adults with AMC (18-25): Moderated by Whitney Foster
ANNUAL CONFERENCE SESSIONS

AMC SESSIONS
A time for AMCe rs, parents of AMCe rs, partners of AMCe rs, and grandparents of AMCe rs 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 AMCe rs, Dads of AMCe rs, Moms of AMCe rs, Adoptive Parents of AMCe rs, and Grandparents of AMCe rs.

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 AND FACE PAINTING WITH CHRIS
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 an AMCer and artist also provides “Face painting with Chris” for all ages. www.artistsguildgalleryofgreenville.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 ages 7 and older, and it is led by an adult sibling of an AMCer, 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. The meeting is scheduled prior to the closing plenary.

CONFERENCE SCHEDULE

CONFERENCE SESSIONS
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, V – Volunteers

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
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<tbody>
<tr>
<td>2:30 PM to 3:30 PM</td>
<td>Volunteer Training</td>
<td>Regent Foyer</td>
<td>V</td>
</tr>
<tr>
<td>4 PM to 7 PM</td>
<td>Registration</td>
<td>Easton Foyer</td>
<td>A</td>
</tr>
<tr>
<td>Time</td>
<td>Session</td>
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<tr>
<td>9 AM to 9:45 AM</td>
<td>Registration</td>
<td>Easton Foyer</td>
<td>A</td>
</tr>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Opening Ceremony with Keynote Speaker Dr. Judith Hall</td>
<td>Easton Ballrooms</td>
<td>A</td>
</tr>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Dr. David Feldman - New Developments in Lower Extremity Surgery in Arthrogryposis and the Future of Upper Extremity Management</td>
<td>Easton Ballroom A</td>
<td>A</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td>First Time Attendee Welcome</td>
<td>Easton Ballroom B</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>1 PM to 3:45 PM</td>
<td>Registration</td>
<td>Easton Foyer</td>
<td>A</td>
</tr>
<tr>
<td>2 PM to 2:45 PM</td>
<td>Dr. Judith Hall - : What’s New in the Genetics of Arthrogryposis</td>
<td>Easton Ballroom A</td>
<td>M</td>
</tr>
<tr>
<td>3 PM to 3:45 PM</td>
<td>Dr. Gary Nortiz - Understanding Pain and Pain Management in Arthrogryposis</td>
<td>Easton Ballroom A</td>
<td>M</td>
</tr>
<tr>
<td>3 PM to 3:45 PM</td>
<td>Dr. Giampietro - What is a Genetic Evaluation and How Will This Benefit My Child and Family?</td>
<td>Easton Ballroom B</td>
<td>M</td>
</tr>
<tr>
<td>3 PM to 3:45 PM</td>
<td>Devin Aumend &amp; Kimberly Chaffin - : A General Overview of OOD Services and Vocational Rehabilitation Sib Shop</td>
<td>Easton Ballroom C</td>
<td>A</td>
</tr>
<tr>
<td>4 PM-4:45 PM</td>
<td>Dr. Kent Williams - Discussion of Gastrointestinal and Nutritional Issues</td>
<td>Easton Ballroom A</td>
<td>M</td>
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<tr>
<td>4 PM-4:45 PM</td>
<td>Adults with AMC - Not Gender specific (18 and over)</td>
<td>Easton Ballroom C</td>
<td>P</td>
</tr>
<tr>
<td>4 PM-4:45 PM</td>
<td>Teens and Tweens- Not Gender specific</td>
<td>Easton Ballroom D</td>
<td>P</td>
</tr>
<tr>
<td>4 PM-4:45 PM</td>
<td>Moms of AMCers 11 and over</td>
<td>Easton Ballroom E</td>
<td>P</td>
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<tr>
<td>Friday, July 6, 2018</td>
<td>Dr. Harold van Bosse - AMC 101 Part 1</td>
<td>Easton Ballroom A</td>
<td>M</td>
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<tr>
<td>9 AM to 9:45 AM</td>
<td>Dr. Reenee Donohoe - Movement is Exercise</td>
<td>Easton Ballroom B</td>
<td>A</td>
</tr>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Misha Walker - Limitless</td>
<td>Easton Ballroom C</td>
<td>A</td>
</tr>
<tr>
<td>10 AM to 10:45 AM</td>
<td>Dr. Therese Willkomm &amp; Caitlyn Fulton - Creating Assistive Technology Solutions in Minutes for Individuals who Experience Arthrogryposis Becky Prince - Come Learn the Sport of Boccia in an Interactive Demo Men with AMC (18 and over) Women with AMC (18 and over)</td>
<td>Easton Ballroom B</td>
<td>M</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td>Dr. Natasha O’Malley - Management Goals and Treatment Options for Knee Issues in AMC</td>
<td>Easton Ballroom A</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, V - Volunteers

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<thead>
<tr>
<th>Time</th>
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<tbody>
<tr>
<td>11 AM to 11:45 AM</td>
<td>Dr. Suzanne Cherry &amp; Dr. Lisa Wagner - Interdisciplinary Approach to treating AMC: Different perspectives and ideas</td>
<td>Easton Ballroom B</td>
<td>M</td>
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<tr>
<td></td>
<td>Dr. Noëmi Dahan-Oliel - Research Update in arthrogryposis: Current and New projects for children and youth</td>
<td>Easton Ballroom C</td>
<td>M</td>
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<tr>
<td></td>
<td>Teens &amp; Tweens with AMC – Male (11-17)</td>
<td>Easton Ballroom D</td>
<td>P</td>
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<tr>
<td></td>
<td>Teens &amp; Tweens with AMC – Female (11-17)</td>
<td>Easton Ballroom E</td>
<td>P</td>
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<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>Robert Page - DIY with PVC</td>
<td>Easton Ballroom A</td>
<td>A</td>
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<td></td>
<td>Don Brown - Ten Steps for Caretakers of Dependents with Special Needs</td>
<td>Easton Ballroom B</td>
<td>A</td>
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<tr>
<td></td>
<td>Dr. Naimisha Shah-Hoffman - Ways to Achieve Dental Health and Function in the World of Arthrogryposis</td>
<td>Easton Ballroom C</td>
<td>M</td>
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<td>Tube Feeding - Support AMC</td>
<td>Easton Ballroom D</td>
<td>M</td>
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<td></td>
<td>Partners of Adults with AMC</td>
<td>Easton Ballroom E</td>
<td>P</td>
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<tr>
<td>3 PM to 3:45 PM</td>
<td>Dads of AMCers</td>
<td>Easton Ballroom B</td>
<td>P</td>
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<tr>
<td></td>
<td>Young Adults with AMC (18-25)</td>
<td>Easton Ballroom C</td>
<td>P</td>
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<td></td>
<td>Amputation a Parent’s Perspective</td>
<td>Easton Ballroom D</td>
<td>M</td>
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<td></td>
<td>Families through Adoption of an AMCer</td>
<td>Easton Ballroom E</td>
<td>P</td>
</tr>
<tr>
<td>4 PM-4:45 PM</td>
<td>Grandparents of AMCers</td>
<td>Easton Ballroom D</td>
<td>P</td>
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<td></td>
<td>Dr. Claire Z. Kalpakjian &amp; Rebecca Parten - Women’s Health &amp; Disability Focus Group</td>
<td>Easton Ballroom E</td>
<td>P</td>
</tr>
<tr>
<td>6:15 PM to PM</td>
<td>1st Annual AMCSI Dinner &amp; Prom - come as you are or dress yourself up - come and have fun with your AMC family!</td>
<td>Easton &amp; *Regent Ballrooms</td>
<td>A</td>
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**Saturday, July 7 2018**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
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<tbody>
<tr>
<td>9 AM</td>
<td>Group Photo</td>
<td>Easton Ballrooms</td>
<td>A</td>
</tr>
<tr>
<td>10 AM to 11 AM</td>
<td>Painting with Theresa and Face Painting with Chris</td>
<td>Regent Ballroom</td>
<td>A</td>
</tr>
<tr>
<td>2PM to 2:45 PM</td>
<td>Annual Meeting, Closing Ceremony, Announcement of 2019 Location</td>
<td>Easton Ballrooms</td>
<td>A</td>
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</tbody>
</table>

**REMINDERS**

- Badges MUST be worn to all conference sessions 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.

- All children 18 years of age and under must be supervised by an adult at all times in the hotel. Children’s Programming is available during conference sessions but is not childcare. Please arrange...
that an individual aged 14 years or older is present and responsible to supervise your child(ren) during all Children’s Programming

- Please use the hashtag #AMCOhio18 when posting to social media!
- 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 conference event. Adult beverages may be purchased and enjoyed at Easton Social Lobby Bar or Easton Town Center.
- 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 treatment ideas as a result of attending this conference.
- During Painting with Theresa, please don’t let children ‘swim’ in the paint 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.

**CHILDREN’S PROGRAMMING THEME: “TOGETHER WE CAN REACH THE STARS”**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>2 PM to 3:30 PM</td>
<td>Balloon Alien making, Paper Airplane target practice, star stamping, Planet Toss, and other space activities.</td>
<td>Regent Ballroom</td>
</tr>
<tr>
<td>3 PM to 5 PM</td>
<td>Handprint/footprint Aliens, Explore Astronaut glove box, Galaxy Photo booth, Alien Plate Mask, Space Tunnel, Alien spaceship craft, and other space activities.</td>
<td>Regent Ballroom</td>
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<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 AM to 9:45 AM</td>
<td>Alien rock craft, Jump ropes, Alien headband craft, hippity hops, and other space activities.</td>
<td>Regent Ballroom</td>
</tr>
<tr>
<td>10 AM to 10:45 AM</td>
<td>Telescope making, Mini Rock Toss, beading, Galaxy Doodles, and other space activities.</td>
<td>Regent Ballroom</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td>Galaxy Box Buddy craft, scooters, Color Your Own Kaleidoscope, and other space activities.</td>
<td>Regent Ballroom</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch - Children’s Programming Closed</td>
<td>Regent Ballroom</td>
</tr>
<tr>
<td>2 PM to 5 PM</td>
<td>Space Activity Books, Kaleidoscope Discovery, Collaborative Spaceship Design, Rocket Playhouse, and other space activities.</td>
<td>Regent Ballroom</td>
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<tr>
<th>Time</th>
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<th>Location</th>
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</thead>
<tbody>
<tr>
<td>After Group Picture - 11 AM</td>
<td>Painting with Theresa and Face Painting with Chris</td>
<td>Regent Ballroom</td>
</tr>
</tbody>
</table>
• 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.
• Please arrange that an individual aged 14 years or older is present and responsible to supervise your child(ren) during all Children's Programming.
• During Painting with Theresa please don’t let children ‘swim’ in the paint. 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.

## REACH FOR THE STARS

| **Kiely-Ann,**  
**WE ARE SO PROUD OF YOU AND YOU’RE A PRETTY AWESOME KID!**  
**WE LOVE YOU BEAUTIFUL PRINCESS!**  
**LOVE, MOM & DAD** | **Reach for the Stars William!**  
**WE ARE SO PROUD OF YOU!**  
**LOVE, MOM, DAD, AND JONATHAN** | **William Gephardt, Grams and Pop Pop are so incredibly proud of all of the amazing things you have accomplished. Keep your star shining bright! We love you, Buddy!** |
|---------------------|------------------------------------------|--------------------------------------------------|
| **Our beautiful granddaughter,**  
**Devin. You are amazing, just the way you are! We love you so very much, Poppa John and Grandma** | **Owen Sedey-you are our superhero!! Love, Aly, Brian, Teddy & Eleanor :)** | **Fire Girl - Keep shining that rainbow you caught with Wahine fingers gathering Pele’s grace in your dance. Moochies and Flys, Mama, Papa, Wenna and Percy.** |
| **AMCSI Board of Directors & Planning Committee, Thank you for your dedication and endless hours of work! You all are Stars! Hugs, Lana** | **Hi Owen!**  
**You are such a strong and amazing kid - I love you to the stars and back. Love, Aunt Carla** |  |
| **To our most favorite AMCer William Gephardt!**  
"Nothing can dim the light which shines from within" - Maya Angelou  
Love, Autumn "Almond" & Gino DosSantos | **Jessica Lappin**  
**Your determination makes us so proud. NEVER GIVE UP!!! Love you Mom & Dad** |  |
FOUNDER: ANI SAMARGIAN

Ani is the proud wife of Darrell Mahan, and mom Aiden, Isabella, Ciaran and her oldest daughter and AMCer, Abby. She serves on the Board of Directors for AMCSI. 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 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, reading and creating with Legos. He currently resides in South Carolina.

SECRETARY: JOEY BALISTRERI

Joey Balistreri is the proud parent of Liam, an incredible three-year old 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.

VICE PRESIDENT OF PROGRAMMING: MICHELE SCHAFFER

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 or “The
Loon Crew.” In her free time, Michele enjoys spending time with her husband and children and singing with The Voices of Ohio. Michele and her family reside in Columbus, Ohio.

**TREASURER: JARED KAMPF**

Jared Kampf and his wife Courtney live in Minnesota and have two sons. He has a Bachelors in Accounting and currently works as an Accountant for a construction company. Courtney is a personal care attendant to her friend with AMC for the past twelve years and has enjoyed going to past two conferences. In his free time Jared enjoys running, playing soccer, and cooking for his family.

**DIRECTOR OF MEDICAL ADVISORY BOARD: HAROLD VAN BOSSE, MD**

Dr. van Bosse missed out on the first AMCSI “convention”, but has been a fixture at the events ever since. He was invited onto the Board of Directors in 2007. He 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. He has written a number of articles and book chapters on AMC, and is organizing the 3rd International Symposium on Arthrogryposis in Philadelphia in September 2018. 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. He recognizes how lucky he is to have a tolerant and supportive wife in Ana, and cherishes the (too little) time he has to spend with his sons Townsend and Harrison, and doggie Valentine.

**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.

**PARLIAMENTARIAN: 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.
MEMBER AT LARGE: MELISSA SNYDER

Melissa Snyder was born with AMC and is affected in all 4 limbs. She resides in Columbia, South Carolina with her boyfriend Cory and their adopted Pitbull mix Gibbs. She is a classically trained Soprano who graduated from The South Carolina Governor’s School for the Arts and Humanities and went on to study Vocal Performance at Mars Hill College. After moving back to SC, Melissa started working at Able SC. It was there that she found her true passion, empowering people with disabilities to lead independent lives. She hopes to finish her degree in Social Work, acquire a MSW, and work with transition aged youth with disabilities.

MEMBER AT LARGE: ALEXIS RECORD

Alexis Record lives in San Diego with her husband, Charles Wesley, their two kids, three kitties, occasional foster kittens, and chickens. After her daughter, Laelia, was born in 2007 with the amyoplasia type of AMC, a doctor informed them it was not genetic so none of their future children would have it. After some initial hardships, they settled into their new normal, but instead of feeling relieved they felt sad that they wouldn’t have another AMGeer in their home. The doctor hadn’t counted on adoption, though! In 2012 Alexis and her husband adopted a two-year old with AMC in all four limbs. In 2014 Alexis 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.

WEBMASTER: LORI CARPENTER

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

INTERNATIONAL AMBASSADOR: MISHA WALKER

Misha “Dream” Walker is a Peruvian inspirational speaker and blogger, and the newly appointed AMCSI international ambassador. Misha currently lives in Lima, Peru with her husband from where she travels the world trying to raise awareness for “arthrogry’what’sis” and visiting as many families as she can from our incredible AMC community. Oh, and she was also born 1 in 3000 AMC Awesome.

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 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

HAROLD VAN BOSSE, MD: DIRECTOR

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.

JUDITH HALL, MD

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 BALEN'T-GEPHARDT: DIRECTOR OF OPERATIONS

Jean, wife to Matt, and mother to William (AMC) and Jonathan, currently lives in Maryland. Jean is an environmental engineer and works for the Federal Government. The Gephardt family has been regular conference attendees 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 business analyst and project manager at the University of Illinois at Chicago and recently completed 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.

LA'SHELL PAGE: DIRECTOR OF CHILDREN’S PROGRAMMING

LaShell Page is a seasoned 1st grade teacher in Oklahoma and mother of a 5-year-old AMCer named Brian and 3-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 third 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.

BETH SELLERS: DIRECTOR OF VOLUNTEER RESOURCES

Beth Sellers is a mom of four, including 10-year-old AMCer, Taylin. Beth is a graduate of James Madison University and Eastern Mennonite University with a Master’s Degree in Education. She has a long career in special education with a specialty in assistive technology. Beth is currently employed as a support coordinator for individuals with disabilities through the local community services board and as an adjunct professor teaching assistive technology courses to undergraduate students at the local university.

CONFERENCE PHOTOGRAPHERS

MICHELLE MOCKERIDGE, JENNIFER WILD, SHERI MOCKERIDGE, AND AMY FLOWERS

If you have conference photographs or videos you would like to share with AMCSI, please send them to AMCohio18@gmail.com or use the hashtag #AMCOhio18 on social media.
Being born with multiple congenital deformities including Arthrogryposis & Prune Belly Syndrome, doctors told his parents that Marty Sheedy wouldn’t make it past the age of three, and, if he did, Marty would never walk or function normally. Well, he proved them wrong!

Today Marty has learned to live every day to the fullest. Some people say that his 60 pounds of body weight is all heart! Marty’s story and drive has touched thousands of hearts and inspire people to face adversity while being able to HELP so many. Marty has overcome his challenges in life as well and has found the “freedom to be happy” as Marty has his own Scissor Gait walk. That walk has given him freedom of mobility that has lead Marty to experiencing a full and rich plethora of experiences. It also serves as a metaphor for others to find their freedom also.

The Project Scissor Gait Foundation is a platform that has helped Marty inspire others as a speaker and representative for those facing the same diagnoses. Funds raised through Project Scissor Gait helps to support individuals diagnosed with Arthrogryposis and Prune Belly Syndrome. Your gift provides these individuals with access to medical conferences, adaptive equipment, care packages, and scholarships.

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Donald T. Brown, ChFC®, ChSNC®, CASL®, makes financial topics fun and interesting. He is highly credited and experienced in retirement, estate, and special needs planning.

He has the unique ability to energize a crowd, make people laugh, and help solve complex financial problems using easy to understand ideas and stories. He finds simplicity is the key to getting people to take action.

As a financial services executive with 26 years of special needs planning experience, Don is uniquely qualified to advise special needs families and the businesses that serve them.

Don frequently speaks to employer groups, non-profit organizations, families and business owners. What makes his presentations unique is the real world experience he draws on to connect with his audience. Don’s talks, coupled with his resources and usable tools have been described as practical, easy to understand, and completely unique.

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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
On behalf of our attendees
The Board of Directors of AMCSI
&
The Conference Planning Team
would like to thank the staff of the
Hilton Columbus at Easton
for their assistance in making the
13th Annual
Arthrogryposis Multiplex Congenita Support Conference
a success.

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BE SURE TO STOP BY
AND SAY HI
TO THE
AMC DADS

AMC Dad's Table in the AMCSI Exhibit Area

Loon Crew:
Once again you ladies both humble and amaze me. Every time I think we've hit a wall, you help figure out a way to break through. I could not do this without you, and I don't want to try! Thanks for the hours you give, and I am honored to call you friends and Loons.

~Michele

AMCSUPPORT.ORG
Arthrogryposis Multiplex Congenita Support, Inc.

Allen, David, Andrew, Christopher & Kayllin.
Thank you for your understanding as I planned for this year's conference...even when I meant cereal for dinner when I got busy and forgot to start dinner, a 7 foot grid covered in sticky-notes on the living room wall, and my endless hours at the computer. I love you all very much!

Mom & Dad: Thanks for travelling once again to lend a hand. I love you.

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

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I WOULD LIKE TO THANK THE BOARD OF DIRECTORS OF ARTHROGRYPOSIS MULTIPLEX CONGENITA SUPPORT, INC. FOR THEIR HARD WORK AND DEDICATION IN THEIR EFFORTS TO SUPPORT FAMILIES AND INDIVIDUALS TOUCHED BY ARTHROGRYPOSIS MULTIPLEX CONGENITA.

DAC&K: Always remember that limitations do not stand up to determination.
Allen C. Schaffer, AIA, LEED AP BD+C, WELL AP, LEED Ambassador

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REGIONAL SUMMARY

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/CALENDAR-2/ TO LOOK FOR A MINI MEET-up NEAR YOU!
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In memory of our AMCer Olivia and all the other angels
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
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Alexis Irellyn Pendak
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Emma Jean Schmidt
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 entire arthrogryposis center team at the Shriners Hospital for Children – Philadelphia supports the mission of the Arthrogryposis Multiplex Congenita Support, Inc, for providing and encouraging the understanding and support for those with arthrogryposis, as well as creating an awareness of AMC. Drs. Harold van Bosse, Scott Kozin, and Dan Zlotolow are committed to using their combined medical experience to help children with arthrogryposis achieve their potential. By bringing the newest treatments and treatment philosophies to bear, they strive to work with their patients and families towards a shared goal of maximizing the child’s capabilities. The team’s ambition is to help their patients navigate the world as thriving independent adults.

For over 90 years, the Shriners Hospitals for Children have been devoted to transforming the lives of children through excellence in quality care, teaching, and research. Located at 3551 North Broad Street, the hospital provides care to children with orthopaedic conditions, spinal cord injuries, and comprehensive and individualized rehabilitation program needs. Children from birth to 18 years old are eligible for care. Acceptance is based solely on a child’s medical needs, regardless of the family’s ability to pay. For more information, please visit us at shrinersphilly.org/info, or to arrange to have your child seen, call 215.430.4140 or email us at PHLnewappts@shrinenet.org.

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