Helping children with arthrogryposis maximize their independence.

At Nemours/Alfred I. duPont Hospital for Children, we are 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.

To make an appointment: (800) 416-4441.
Learn more at Nemours.org.
A NOTE FROM OUR FOUNDER

Dear AMC Family,

Welcome to Norfolk! We are happy that you have joined us for the 14th Annual Arthrogryposis Multiplex Congenita Support, Inc. (AMCSI) Conference! The next three and a half days will be full of great information, networking and support. This year we’re offering some exciting sessions, including adaptive technology, current research regarding arthrogryposis, as well as our support sessions.

I extend my warmest welcome to our first-time attendees. Your first conference can feel overwhelming with so many new faces and seeing so many people reconnecting with friends they see only once a year. Please remember that AMCSI started as a SUPPORT group, and we want you to feel that you are a part of the family. If you have questions, please reach out to a member of the Conference Planning Team, Board of Directors (BOD) or another attendee. We’re a friendly group! We hope that this weekend will be memorable for all of you.

A very warm “Thank You” to all our speakers, presenters, and Exhibitors! We could not host this event without your generous donations of time, talent and financial support.

I also need to thank the Conference Planning Team and the AMCSI Board of Directors, for their commitment to our AMC Community. Your countless hours of work not only at the conference but also behind the scenes is unimaginable for those who are not involved. The Planning Team works year-round and goes non-stop during the event. If they seem to be ignoring you, it is simply because they are focused on the next item on their never-ending “To Do” list. If you have a question or concern, please voice it in a respectful and kind manner, if you think they are doing a great job, tell them - if you can get them to slow down and talk!

I am thankful for each and every one of you who traveled many miles to be with us in Norfolk, Virginia. 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 Congenital Support, Inc.
A NOTE FROM THE PLANNING COMMITTEE

Dear Friends,

The 2019 Conference Committee would like to welcome you to the 14th Annual Arthrogryposis Multiplex Congenita Support, Inc. conference in Norfolk, Virginia! We are so happy that you are here, this year is one of our largest conferences to date with over 500 attendees, speakers and staff registered! If you are a first-time attendee, WELCOME! We've been told our conference has a “Unique” atmosphere, 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 volunteer. We could not offer the programming that we do without your help. Volunteers are what make this conference happen. We can plan, but without YOU we couldn't follow through. THANK YOU! We would also like to welcome three new members of the Planning Team or “Loon Crew.” Jennifer Sander, Larina Swanson-Carter and Ana van Bosse have joined our team to assist us as we continue to grow. We are very happy to have them join our team.

This year, we are trying a few new initiatives, some you will notice and others are behind the scenes. By now, you have noticed that we did not provide paper copies of the program. This was done for a few reasons. The first was cost. We are always looking for a way to keep costs as low as possible, and a digital program is very cost-effective. By eliminating extensive printing, we net an annual savings of almost $2000. Second, it is better for the environment. Every year we end up seeing programs in the trash, and we want to keep our environmental impact to a minimum. Finally, many individuals prefer to use their phones/tablets, we listened to our survey feedback and decided to trial a digital program this year.

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

We 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.

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

Welcome to Norfolk!
Your 2019 Conference Planning Team

Warmly,

Michele Schaffer, Vice-President of Programming
Jean Balent-Gephardt, Director of Operations
Betsy Gates-Ehlers, Director of Logistics
LaShell Page, Director of Children’s Programming
Beth Sellers, Director of Volunteers
Ani Samargian, Founder
Larina Swanson Carter
Ana van Bosse
Jen Sander
A NOTE FROM OUR PRESIDENT

It is with great pleasure that the BOD and I welcome you to Norfolk, Virginia, and The Hilton Norfolk The Main hotel for the 14th annual Arthrogryposis Multiplex Congenita Support, Inc., conference!

I am very excited to be with you for this weekend. There is nothing more rewarding than seeing your smiling faces, our kids playing, AMC adults interacting, and our families supporting one another each year.

I am amazed at how much our support group has changed since 2008, when I came to my first conference in Ohio. From mini-meetups to fundraisers our families are reaching out to one another in so many ways. I have also seen great responses to families not only in need of support during surgeries, hospital stays, and sickness, but also to celebrate our AMCers who have graduated, reached milestones, or accomplished “firsts” that most people would take for granted. These awesome connections have helped form lifelong bonds and friendships, which I hope will continue and grow over the next few days.

As conferences before, we have many first-time attendees. On behalf of the Board of Directors of Arthrogryposis Multiplex Congenita Support, Inc., and the Conference Planning Team, I welcome you! It may seem very overwhelming, but please pace yourselves and feel free to ask us or other “old-timer” attendees questions; we are open and willing to answer any of your questions. Please attend our workshops and children’s activities that interest you most. We want you to feel comfortable and welcomed into our family.

I would also like to extend a warm welcome to our speakers, presenters and vendors. Thank you for taking time out of your busy schedules to provide our families with valuable information.

I would also like to thank the AMCSI Board of Directors for your dedication and commitment to our families and acknowledge the many volunteer hours that you put in to seeing AMCSI’s mission and vision flourish. I would like to offer a special thank you to the Conference Planning Team who volunteered countless hours of work to provide our families with a memorable and informative conference.

Finally, I would like to thank our amazing families, AMCSI members, Facebook page administrators, and donors. Without your generous support each year, AMCSI would not be where we are today. Your generous support and dedication to Arthrogryposis Multiplex Congenita Support Inc., makes my heart happy; AMCSI is eternally grateful for each one of you! THANK YOU!

Sincerely,

Chris Hartwick,
President
Arthrogryposis Multiplex Congenita Support, Inc.
DON BROWN
With over 30 years’ experience, Don is considered a thought leader in Special Needs Planning. He is a member of the Academy of Special Needs Planners as well as a lifetime member for the Million Dollar Round Table (MDRT). Don is also the founder of the Special Needs Funding Coach, www.SPECIALNEEDSFUNDINGCOACH.COM.

**Presentation: Your Dependent with AMC: Making Their Future More Secure.** This newly updated step by step workshop will address critically important issues of: retaining eligibility for government support programs, planning for a quality of life and lifetime of care for your dependent after you are gone, and maximizing your resources so you don't sacrifice your own financial security in the process. Presented in a practical, easy to understand, and entertaining fashion, Don Brown will provide a unique experience for those who attend.

My Notes

---

TRICIA BUCCI
Tricia Bucci, MPT, has been a physical therapist at Shriners Hospitals for Children-Erie and now, Shriners Hospitals for Children-Greenville for a combined 21 years. Areas of interest include; training in French Functional Method of treatment for clubfeet at Texas Scottish Rite Hospital, treatment for infants with torticollis/plagiocephaly, serving as a clinical education coordinator, and most recently, serving as a member of the AMC team at Shriners Hospitals for Children in Greenville.

**Presentation: A Multi-disciplinary Approach to Rehabilitation across the Age Continuum.** A multi-disciplinary approach to rehabilitation is essential to individuals with AMC achieving theiir fullest potential with motor skills and independence with ADLS. The intensity and focus of rehabilitation does change across the age continuum. We will discuss our multi-disciplinary approach at 4 stages of life, including infant, toddler, school age and teenage/adult years. We look forward to a collaborative discussion regarding how a team approach to rehabilitation better serves the individual with AMC. (Joint Presentation with Lisa Wagner).

My Notes
JESSICA COLLINS, OT
Jessica Collins is an Occupational Therapist at Shriners Hospital for Children-Canada since 2018. She graduated from McGill University in 2015. Since starting at the Shriners Hospital for Children-Canada she is also working as a research assistant, on research devoted to improving clinical interventions for children living with physical disabilities, such as arthrogryposis. Her previous work experience includes developing a rehabilitation program at Fondation Papillon and as an occupational therapist at Mackay Rehabilitation Center. Jessica is passionate about exchanging with youth and their families and improving quality of life.

Presentation: Sharing is FUN: Update on current projects. Target: Youth, parents and anyone interested in research in children with arthrogryposis. In this session, Noémi and Jessica will present updates on the following research projects: AMC Registry: Findings from the pilot project and 4-year expansion, Telerehabilitation with AMC: pilot project in progress, and PhotoVoice project: Findings from summer 2018 and upcoming plans for summer 2019. (Joint Presentation with Dr. Noémi Dahan-Oliel).

My Notes

NOEMI DAHAN-OLIEL, PHD
Dr. Noémi Dahan-Oliel is a Clinician Scientist at Shriners Hospital for Children-Canada and Associate Professor McGill University, School of Physical and Occupational Therapy since 2014. Her research program focuses on improving clinical outcomes for children living with musculoskeletal conditions. Research designs include mixed-methods, stakeholder engagement and knowledge translation. Together with a wonderful multidisciplinary and multisite research team, she obtained funding for seven clinical research projects in arthrogryposis. These projects include developing a registry for children with arthrogryposis, piloting a home exercise program using an internet platform, using PhotoVoice to engage with adolescents living with arthrogryposis.

Presentation: Sharing is FUN: Update on current projects. Target: Youth, parents and anyone interested in research in children with arthrogryposis. In this session, Noémi and Jessica will present updates on the following research projects: AMC Registry: Findings from the pilot project and 4-year expansion, Telerehabilitation with AMC: pilot project in progress, and PhotoVoice project: Findings from summer 2018 and upcoming plans for summer 2019. (Joint Presentation with Jessica Collins)

My Notes
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. Reenee has been the primary PT in the arthrogryposis program at the hospital since 1989 and the clubfoot program since 2009. In addition, Reenee spent 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 tall 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: AMC Research and What It Means to You. This session will spend time reflecting on some recent projects that have been worked on at Nemours including predicting ambulation based on strength and position as a new born as well as management of relapsed clubfeet. It will include stretching strategies to help mobilize feet between cast changes. There will be a discussion on the importance of research and why it is so hard to get new projects moved forward. Come hear how you can be a part of it.

My Notes

CAROLINE ELFASSY, PhD. Candidate, MSc. OT (C), erg.

Caroline Elfassy is an Occupational Therapist and Research Assistant at Shriners Hospital for Children - Canada since 2016. She graduated her BSc and MSc A and is currently pursuing her Doctoral studies at McGill University in Rehabilitation Sciences. Her thesis will focus on developing and creating an upper extremity outcome measure specifically for children and youth with AMC. Since starting at Shriners, Caroline has always had an interest in musculoskeletal conditions and developed a particular passion for improving the quality of life for children living with AMC.

Presentation: Development of an Upper Extremity Evaluation for Children with AMC: Phase 1. Target: youth, parents or caregivers, clinicians, and anyone interested in research in children with AMC. During this focus group, Caroline will present previously developed outcome measures and evaluation for children and determine if the items of these tools could be applied to children with AMC. During this open discussion, interested participants will be asked if these items are representative and meaningful for their rehabilitation.

My Notes
DAVID S. FELDMAN, MD
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. Dr. Feldman is an expert in the care of AMC and related disorders. He has revolutionized the care of the Hip and Knee in this patient population, allowing for increased motion and better function.

Presentation: The Hip and Knee. What we have learned by elimination of the external fixator and treating both joints simultaneously. As well: Can we obtain Bicep function (Flexion) of the elbow in AMC?

CAITLYN FULTON
Caitlyn Fulton graduated from the University of New Hampshire with a degree in Economics in 2014, and recently took courses in mathematics in pursuit of a career teaching high school math. During her most recent time at UNH, she discovered a passion for disability justice and accessibility, and has brought awareness to various access issues around campus through the organization she founded, UNH Access4All. She is currently employed at the Assistive Technology Lab through the UNH Institute on Disability under Dr. Therese Willkomm.

Presentation: Making Solutions in Minutes for Limited Hand Function – A Make and Take Workshop. This session will discuss and demonstrate how hundreds of devices can be created in minutes for individuals who experience limited use of their hands. In addition, each person will fabricate a multi-use, portable collapsible book, kindle, iPad, cellphone holder that can be taken home. Live demonstrations on how to make “Hands-Free” eating and drinking solutions; ball launchers; and Table Top slide in Scissors platforms and more will also be conducted during this workshop. Discover new tools, materials and techniques for rapid fabrication of solutions for everyday challenges. (Joint Presentation with Dr. Therese Willkomm).

My Notes
PHILIP F. GIAMPIETRO, MD, PHD

Philip F. Giampietro, MD, PhD, is a professor in the Department of Pediatrics at Robert Wood Johnson School of Medicine. He received his B.S. in Biological Sciences at State University of New York at Stony Brook, Doctorate in Biomedical Sciences at the City University of New York and M.D. at the State University of New York at Stony Brook. Dr. Giampietro completed his internship in Pediatrics at the State University of New York at Stony Brook, 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 Drexel University College of Medicine, 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.

LAUREN HYER, MD

Dr. Lauren Hyer is a pediatric orthopedic surgeon at Shriners Hospital for Children in Greenville, SC, where she joined staff in the Fall of 2016. Noticing a void in the care of children with arthrogryposis, Dr. Hyer started an “AMC clinic” in Spring 2017, and her AMC practice has been growing ever since. Dr. Hyer’s primary focus is the lower extremity, but she has a developing interest and is learning techniques for the upper extremity in hopes to provide full service orthopedic care for her patients. Outside of work, Dr. Hyer enjoys adventuring with her husband, Garrett, and 20-month-old son, Brecken.

Presentation: Building your AMC Team—“The Greenville Method”. Arthrogryposis is a complex condition often involving both upper and lower extremities and at times more. Optimal care includes a team-based
approach involving orthopedics, physical/occupational therapy, and orthotics, among other disciplines. This presentation will go over how to build a family-centered team to care for your child through infancy, toddlerhood, and the school-years. The “Greenville” approach to management will be woven into the discussion, with highlights of surgical techniques for the lower extremity.

SHANNON LA SPINA, PT, DPT

Shannon La Spina, PT, DPT is a Physical Therapist at Bon Secours Richmond Hope Therapy Center and is board certified in Pediatric Physical Therapy. She has advanced training in Intensive PT, Therasuit, Pediatric gait analysis, and in integrated manual therapy through Great Lakes Seminars, and enjoys assisting with the VCU school of PT pediatric curriculum. Shannon received her clinical Doctorate of Physical Therapy in 2004 from Virginia Commonwealth University and was a fellow in the VCU Leadership Excellence in Neurodevelopmental Disabilities (VA-LEND) program while there. She graduated with an undergraduate degree in psychology/sociology from Roanoke College. Shannon is a member of the American Physical Therapy Association and has been active in the local district and at the state level, serving as district director from 2008-2011. Shannon is married with three children, and enjoys distance running, being outside, and cooking.

Presentation: Using the Intensive Therapy Model in the Management of Arthrogryposis. This presentation will discuss the history, premise, and the specifics of the Intensive Therapy model, as it is used at Bon Secours Richmond Hope Therapy and at other sites worldwide. Topics to be discussed include the Intensive physical therapy model, working with other disciplines, suit therapy, differences between intensive and traditional outpatient, current evidence, and how the model can serve patients with Arthrogryposis. Several case studies will be presented, as well as information on how traditional outpatient clinics can incorporate this model of care into their setting.
SARAH LEMIN, MD

Dr. Lemin earned her bachelor’s degree in Molecular Genetics from The Ohio State University and her Doctor of Medicine degree from Northeast Ohio Medical University. She is board certified in OB/GYN and has a private group practice near Cleveland OH. She and her husband Ian have five children, including their youngest who was born with arthrogryposis in 2017. Dr. Lemin has an interest in the prenatal diagnosis of AMC and is working to promote awareness and education among obstetric and pediatric healthcare providers.

Presentation: “AMC and the Prenatal Experience”. Arthrogryposis Multiplex Congenita can be difficult to detect during pregnancy and often goes undiagnosed until after birth. Many obstetric healthcare providers are unfamiliar with AMC and therefore ill-equipped to counsel families on prognosis and expectations. We will present the results of a survey of over 300 AMC families about the care they received during and after their pregnancy. We will discuss the development of an even more in-depth survey and how we hope to use the results to educate healthcare providers, promote awareness of AMC, and develop standardized protocols for providing care during pregnancies affected by AMC.

My Notes

L. REID NICHOLS, MD

L. Reid Nichols, M.D., is a pediatric orthopaedic surgeon at the Nemours/Alfred I. duPont Hospital for Children and the Alfred I duPont Hospital for Children Surgery, Center, Bryn Mawr. She received her undergraduate degrees from the University of Virginia and from Johns Hopkins University School of Nursing. She earned her medical degree from Northeastern Ohio Universities College of Medicine. After graduating from residency in orthopaedic surgery at Maimonides Medical Center in Brooklyn, NY, she completed a fellowship in limb reconstruction at the International Center for Limb Deformity in Baltimore, MD. Under the supervision of John Herzenberg, M.D., a master in the Ponseti technique, she received advanced training in the management of clubfeet. She received advanced training in pediatric orthopaedics with the completion of a fellowship at the Alfred I. duPont Hospital for Children. She is active in many societies including the Pediatric Society of North America, Limb Lengthening and Reconstruction Society, American Academy of Orthopaedic Surgeons, and the Ruth Jackson Orthopaedic Society. Dr. Nichols’ clinical interests include limb deformity and reconstruction, clubfoot, arthrogryposis and pediatric trauma. She serves as the director of the Clubfoot Clinic and co-director of the arthrogryposis clinic.
Presentation: Watching, Waiting, and Working to get the Best Outcomes. Arthrogryposis management watching and waiting is sometimes part of getting a great outcome. A baby born with arthrogryposis often presents with many orthopedic alignment issues that could easily be realigned with multiple surgical techniques. From a parent aspect, it is often scary to think of surgery but also it seems like if surgery could fix things, why not do it early and be done? The key is to make sure the timing of the surgical intervention matches the child's needs. Addressing feet early is standard practice. When it comes to knees, hips, and upper extremities, there is no consensus to when to address each deformity. Working with a multidisciplinary team which includes gait lab, genetics, orthopedics, physical therapy, occupational therapy, osteopathic manipulation, and the family creates the best environment for positive outcomes. This talk will discuss examples of how waiting and watching can produce excellent outcomes with less surgical intervention.

MICHAEL PACKER, MD
Dr. Michael G. Packer is a board certified urologist who specializes in pediatric urology. He is a graduate of Harvard College, and he received his medical degree from Columbia University College of Physicians & Surgeons. He completed his training with a fellowship in Pediatric Urology at the Children's Hospital of Philadelphia. Dr. Packer is an Associate Professor of Urology/Pediatrics at Temple University. He is affiliated with Shriners Hospital Philadelphia, Abington Memorial Hospital, and St. Christopher's Hospital for Children. Dr. Packer was a founding member of International Volunteers in Urology (ivumed.org), a non-profit that provides access to urology care for children and adults in need all around the world. Dr. Packer has been in practice for more than 30 years.

Presentation: AMC and Urologic Issues. The presentation will address urologic issues that may affect patients with AMC, including neurogenic bladder, dysfunctional voiding, urinary incontinence, renal problems and undescended testes.
ASHLEY PIGFORD

Ashley is the Director of the Interaction Design Graduate Program and Associate Professor at the University of Delaware. In his practice-based research, he studies relationships between people and technology through tangible interaction design. His work involves the creation of technology to assist, augment and amplify people’s experience of life. He is an accomplished educator and designer and lectures widely about his pedagogy and creative research projects. He received his MFA in Graphic Design from the RISD in 2006 and his BS in Visual Communications from the University of Delaware in 1996. From 1996-2003 he was Co-founder and Creative Director of Meat and Potatoes, a graphic design company in Los Angeles, CA.

Presentation: Adaptive Technology: From D.I.Y. to Low-Cost Robotic Solutions to Independent Eating. Ashley John Pigford, Associate Professor of Interaction Design at University of Delaware, and Ms. Tracy Shank, Hand Therapist/Occupational Therapist at Nemours A.I. DuPont Hospital for Children, will present a range of ideas and devices they have developed and discovered, specifically related to assistive eating strategies and solutions for people with AMC (all ages). The goal of their work is to provide parents and caregivers with alternatives to expensive, commercial products by sharing information, instructions and access to ongoing research projects. Utilizing off-the-shelf hardware components and open-source technologies and resources, Pigford and Shank plan to distribute what they have learned to participants and incite a community of engaged, maker-minded people to share knowledge and ideas. We hope that this presentation will stimulate discussion and sharing of experiences so that we can all learn from each other. (Joint Presentation with Tracy Shank).

My Notes

TRACY SHANK, MS, OTR/L, CHT

Tracy Shank, MS, OTR/L, CHT is a pediatric hand therapist with 24 years of experience working with a wide range of patient populations. She has worked at Nemours A I DuPont Hospital for Children in Wilmington, Delaware since 2012 where she routinely works with clients with AMC to provide post-Surgical therapy, splinting, and ADL training. Ms. Shank has been published in the Journal of Hand Therapy and the Open Journal of Occupational Therapy as well as rehabilitation engineering journals on topics related to use of the Wilmington Robotic Exoskeleton as well as treatment outcomes based on her work with Interactive Metronome ®. She has authored 3 book chapters on topics related to upper extremity therapy management. Ms. Shank also worked for five years as an Adjunct Professor teaching Functional Anatomy at Thomas Jefferson University’s East Falls Campus which was one of the most rewarding activities in her career.
Presentation: Adaptive Technology: From D.I.Y. to Low-Cost Robotic Solutions to Independent Eating. Ashley John Pigford, Associate Professor of Interaction Design at University of Delaware, and Ms. Tracy Shank, Hand Therapist /Occupational Therapist at Nemours A.I. DuPont Hospital for Children, will present a range of ideas and devices they have developed and discovered, specifically related to assistive eating strategies and solutions for people with AMC (all ages). The goal of their work is to provide parents and caregivers with alternatives to expensive, commercial products by sharing information, instructions and access to ongoing research projects. Utilizing off-the-shelf hardware components and open-source technologies and resources, Pigford and Shank plan to distribute what they have learned to participants and incite a community of engaged, maker-minded people to share knowledge and ideas. We hope that this presentation will stimulate discussion and sharing of experiences so that we can all learn from each other. (Joint Presentation with Ashley Pigford).

My Notes

JESSIE SMITH, C.C.L.S.

Jessie Smith is a Certified Child Life Specialist at The Paley Institute. She provides psychosocial support for pediatric patients and families with rare orthopedic conditions throughout their healthcare journey.

Presentation: Child Life. Pediatric patients with Arthrogryposis receive medical treatments that can increase risks of fear, anxiety, and long-term implications of negative medical experiences. Certified Child Life Specialists are trained medical professionals who work as part of the multidisciplinary team and focus on the psychosocial needs of pediatric patients and families. This presentation aims to equip attendees with awareness of pediatric patient vulnerabilities and interventions to support pediatric patients, siblings, caregivers, and staff.

My Notes
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. Dr. van Bosse also serves as the Medical Advisor for AMCSI.

Presentation: AMC 101. 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. It will also touch upon some of the procedures done to correct lower extremity deformities.

Presentation: Let’s get this straight! AMC and scoliosis. The incidence of scoliosis in children with arthrogryposis multiplex congenita is about 20%. Babies can be born with curves, or they can develop at any time during childhood. In this talk, we will discuss the various ways that spine curves can present, and options for treatment, including bracing, spine casting, non-fusion (“growth friendly”) implants, and spinal fusions.

My Notes

LISA WAGNER, OT

Dr. Lisa V Wagner DHS, OTR/L received her OT degree from the Medical University of South Carolina and her doctorate from the University of Indianapolis. Working for Shriners Hospitals for Children for the past 28 years has allowed Lisa to participate in various research projects resulting in peer-review articles, book chapter and the ability to speak nationally and internationally. She has co-developed three distinct outcome measures including the UBET, SHUEE and SCUES. She is a clinical instructor for the Assisting Hand Assessment. Passionate about children with AMC, she is currently collaborating on an outcome assessment for better understanding of the upper extremities.

Presentation: A Multi-disciplinary Approach to Rehabilitation across the Age Continuum. A multi-disciplinary approach to rehabilitation is essential to individuals with AMC achieving their fullest potential with motor skills and independence with ADLS. The intensity and focus of rehabilitation does change across the age continuum. We will discuss our multi-disciplinary approach at 4 stages of life, including infant, toddler, school age and teenage/adult years. We look forward to a collaborative discussion regarding how a team approach to rehabilitation better serves the individual with AMC. (Joint Presentation with Triccia Bucci).
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’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: The Long Road to AMC Awareness. This session will discuss Misha’s recent roadtrip across the US for AMC Awareness.

THERESE WILLKOMM, PHD, ATP

Dr. Therese Willkomm, PhD, is the Director of New Hampshire’s State Assistive Technology Program with the Institute on Disability at the University of New Hampshire (UNH) and is a clinical associate professor in the Department of Occupational Therapy where she teaches eight different Assistive Technology courses and oversees the Graduate Certificate in Assistive Technology. She is known nationally and internationally for her innovative strategies for creating solutions in minutes. She has designed and fabricated over two thousand solutions for individuals with disabilities. She has presented her work in 42 states, ten foreign countries and three U.S. Territories.
Presentation: Making Solutions in Minutes for Limited Hand Function – A Make and Take Workshop. This session will discuss and demonstrate how hundreds of devices can be created in minutes for individuals who experience limited use of their hands. In addition, each person will fabricate a multi-use, portable collapsible book, kindle, iPAD, cellphone holder that can be taken home. Live demonstrations on how to make “Hands-Free” eating and drinking solutions; ball launchers; and Table Top slide in Scissors platforms and more will also be conducted during this workshop. Discover new tools, materials and techniques for rapid fabrication of solutions for everyday challenges. (Joint Presentation with Caitlyn Fulton).

My Notes

DAN ZLOTOLOW, MD

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

Presentation: A Parent’s Guide to the Upper Extremity in Arthrogryposis. This talk will discuss the more common shoulder, elbow, forearm, wrist, and hand difficulties that face children with Arthrogryposis. Each body part will be considered both independently and how it affects global arm function. Rehabilitation and surgical treatment options will be reviewed.

My Notes
EXHIBITORS

Please visit our Exhibitors located in the Foyer on the Fourth Floor

- AbleNow
- Angel Flight East
- AMC Adult Registry
- AMC Dad’s Calendar
- Don Brown
- Dr. Therese Willkomm
- Permobil
- Obi
- Shriners Hospital for Children - Greenville and Headquarters locations
- Theresa Lucas
- Valerie Pepe

PEER SUPPORT SESSIONS

Adults with AMC: Moderated by Donna Babcock
Adoption: Moderated by Doug and Tracy Hoffman
Dads of AMCers: Moderated by Jonathan Heckert
Grandparents: Moderated by Lois Ann Balent & Karen Gephardt
The Grief Process: Moderated by Maureen Goede
Men with AMC: Moderated by Robert Heimark
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 Maureen Goede and Sian Foster
Significant Others of AMCers: Moderated by Vonda Bahr
Teens and Tweens (Not Gender Specific): Moderated by Carlos Rich and Rachel Schickowski
Teens and Tweens with AMC-Boys: Moderated by Stetson Bardfield
Teens and Tweens Girls with AMC: Moderated by Theresa Lucas
Women with AMC: Moderated by Theresa Lucas
Young Adults with AMC (18-25): Moderated by Whitney Foster
CONFERENCE MEETING SPACE

PEOPLE REMEMBER

- An adult MUST supervise ALL children under the age of 14 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 remember we can 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. 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-positis challenge may NOT take place at the hotel. We know it would be fun, but the staff would not appreciate your mess.
**ANNUAL CONFERENCE SESSIONS**

*First Time Attendee Session*
We know attending your first conference can be overwhelming. To help you feel more comfortable, please join us after the opening ceremony to learn about the conference, who we are and how this all works.

*AMC Meet and Greet*
All attendees are welcome to meet and mingle in the lobby of the hotel. Members of the AMCSI Board and Directors and Conference Planning team will be present, so please say hi!

*AMC Peer Support Sessions*
A time for AMCers, parents of AMCers, partners of AMCers and grandparents of AMCers 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 AMCers, Dads of AMCers, Moms of AMCers, Adoptive Parents of AMCers, and Grandparents of AMCers.

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*
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. Children 17 & Under will receive a single 8X10 canvas. Adult AMCers will have access to a limited number of 5X7 canvases. www.theresalucas.com

Chris Hartwick, AMCer/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 -10 years old and older.

*AMCSI Group Dinner*
On Thursday evening, all conference attendees will be invited to join a group “Picnic Dinner.” This annual event brings all attendees together in a casual setting to enjoy our indoor picnic.

*AMCSI Prom*
Come as you are or dress up in your best. All are welcome at the prom. Join us for a fun evening of fellowship as we show off our best moves and dance the night away in a family friendly atmosphere.

*Annual Public Meeting*
Open to all AMCSI conference attendees. Come learn what YOUR Board of Directors is doing to follow our mission and vision.
# Children’s Programming

**Reminders:**

- An adult MUST supervise ALL children under the age of 18 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. 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.

*Remember the Schedule is Subject to Change*

## Thursday, July 4, 2019

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 PM to 3:30 PM</td>
<td><strong>Meet and Greet Zoo animals:</strong> Come meet and learn about the local zoo animals! There will be three sessions available. Each session will be limited to 40 guests. Sessions will be: 2pm-2:30pm, 2:30pm-3pm, and 3pm-3:30pm. Guest will be only allowed to attend one session. Additional activities will be available for those not attending the zoo session including Chaney Sing Alongs every 30 minutes.</td>
<td>Salon G</td>
</tr>
<tr>
<td>3:30 PM to 3:45 PM</td>
<td><strong>Family Game Time:</strong> Ker Plunk, Hot Potato, Jenga, Candyland, Hedbandz, Sorry, Trouble, Uno, etc.</td>
<td>Salon G-H</td>
</tr>
</tbody>
</table>

## Friday, July 5, 2019

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 AM to 9:45 AM</td>
<td><strong>Superhero Crafts &amp; Activities:</strong> superhero hand prints, photo booth, superhero paper bag craft, pool noodle Pom Pom shooters, make Captain America’s shield, etc.</td>
<td>Salon G-H</td>
</tr>
<tr>
<td>10 AM to 10:45 AM</td>
<td><strong>Superhero Craft &amp; Activities:</strong> make a superhero bracelet, gliders, superhero play packs, superhero stencil art, etc.</td>
<td>Salon G-H</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td><strong>Superhero Crafts &amp; Activities:</strong> make your own mask, spider web toss, make your own superhero paddle ball, superhero magic scratchers, etc.</td>
<td>Salon G-H</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch - Children’s Programming Closed</td>
<td>Salon G-H</td>
</tr>
<tr>
<td>2 PM to 3:45 PM</td>
<td><strong>Superhero Visitors (2pm-3pm):</strong> Come meet some of your favorite superheroes for photos <strong>Superhero Training Camp:</strong> Weightless boulder lifting, Weightless weightlifting, Hulk Brick smashing, Weightless tiring rolls, etc.</td>
<td>Salon G-H</td>
</tr>
</tbody>
</table>

## Saturday, July 6, 2019

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approximately 10 AM to 11:30 AM</td>
<td>Painting with Theresa and Face painting with Chris</td>
<td>Salon G-H</td>
</tr>
</tbody>
</table>

---

20
## Conference Schedule

### Wednesday, July 3, 2019

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>2:30 PM to 3:30 PM</td>
<td>Volunteer Training</td>
<td>Foyer</td>
<td>V</td>
</tr>
<tr>
<td>4 PM to 6 PM</td>
<td>Check In</td>
<td>Foyer</td>
<td>A</td>
</tr>
<tr>
<td>7:15 PM to 10 PM</td>
<td>Meet and Greet</td>
<td>Hotel Lobby</td>
<td>A</td>
</tr>
</tbody>
</table>

### Thursday, July 4, 2019

<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>Check In</td>
<td>Foyer</td>
<td>A</td>
</tr>
<tr>
<td>10 AM to 10:45 AM</td>
<td>Opening Ceremony</td>
<td>Salon D E</td>
<td>A</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td>Check In</td>
<td>Foyer</td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>Dr. Dan Zlotolow - A Parent’s Guide to the Upper Extremity in Arthrogryposis</td>
<td>Salon D</td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>First Time Attendee Welcome</td>
<td>Salon E</td>
<td>N</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch on your own</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>1 PM to 3:45 PM</td>
<td>Check In</td>
<td>Foyer</td>
<td>A</td>
</tr>
<tr>
<td>2 PM to 2:45 PM</td>
<td>Noémi Dahan-Oriel with Jessica Collins - Sharing is FUN: Update on current projects</td>
<td>Salon B</td>
<td>R</td>
</tr>
<tr>
<td></td>
<td>Adults with AMC - CoEd</td>
<td>Salon C</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Dr. Harold van Bosse - AMC 101</td>
<td>Salon D</td>
<td>N</td>
</tr>
<tr>
<td></td>
<td>Dr. Reid Nichols - Watching, Waiting, and Working to get the Best Outcomes</td>
<td>Salon E</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Siblings of AMCers (10 and older)</td>
<td>Salon F</td>
<td>P</td>
</tr>
<tr>
<td>3 PM to 3:45 PM</td>
<td>Caroline Elfassy - Development of an Upper Extremity Evaluation for Children with AMC: Phase 1</td>
<td>Salon B</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Grandparents of AMCers</td>
<td>Salon C</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Dr. Lauren Hyer - Building your AMC Team - “The Greenville Method”</td>
<td>Salon D</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Reenee Donohoe - AMC Research and What It Means to You</td>
<td>Salon E</td>
<td>P</td>
</tr>
<tr>
<td>6:30 PM-8:30 PM</td>
<td>Group Dinner</td>
<td>Main Ballroom</td>
<td>A</td>
</tr>
</tbody>
</table>

### Friday, July 5, 2019

<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>Check In</td>
<td>Foyer</td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>Dr. Sara Lemin - AMC and the Prenatal Experience</td>
<td>Salon B</td>
<td>R</td>
</tr>
<tr>
<td></td>
<td>Ms. Maureen Goede, Compassionate Friends: Grief - The Process</td>
<td>Salon C</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Michael Packer - AMC and Urologic Issues</td>
<td>Salon D</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Dr. David Feldman - The Hip and Knee</td>
<td>Salon E</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Young Adults with AMC (18-30)</td>
<td>Salon F</td>
<td>P</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
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 AM to 10:45 AM</td>
<td>Don Brown - Your Dependent with AMC: Making Their Future More Secure.</td>
<td>Salon B</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Moms of AMCers 11-UP</td>
<td>Salon C</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Misha Walker (AMCSI International Ambassador) - The Long Road to AMC Awareness</td>
<td>Salon D</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Lisa Wagner and Tricia Bucci - A Multi-disciplinary Approach to Rehabilitation across the Age Continuum Boys with AMC (12-17)</td>
<td>Salon E</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Salon F</td>
<td>P</td>
</tr>
<tr>
<td>11 AM to 11:45 AM</td>
<td>Girls with AMC (12-17)</td>
<td>Salon B</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Moms of AMCers 10-under</td>
<td>Salon C</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Shannon La Spina - Using the Intensive Therapy Model in the Management of Arthrogryposis</td>
<td>Salon D</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Ashley Pigford and Tracy Shank - Adaptive Technology: From D.I.Y. to Low-Cost Robotic Solutions to Independent Eating</td>
<td>Salon E</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Men with AMC (18-over)</td>
<td>Salon F</td>
<td>P</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch on your own</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>2 PM to 2:45 PM</td>
<td>Significant others with AMC</td>
<td>Salon B</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Dads of AMCers</td>
<td>Salon C</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Dr. Phil Giampietro - What is a Genetic Evaluation and How Will This Benefit My Child and Family?</td>
<td>Salon D</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Dr. Therese Willkomm with Caitlyn Fulton - Making Solutions in Minutes for Limited Hand Function - A Make and Take Workshop (2pm-3:45pm)</td>
<td>Salon E</td>
<td>R</td>
</tr>
<tr>
<td></td>
<td>Women with AMC (18-Over)</td>
<td>Salon F</td>
<td>M</td>
</tr>
<tr>
<td>3 PM-3:45 PM</td>
<td>Dr. Harold vanBosse - Let's get this straight! AMC and scoliosis</td>
<td>Salon B</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Dads of AMCers</td>
<td>Salon C</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>Jessie Smith - Child Life</td>
<td>Salon D</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Dr. Willkomm with Caitlyn Fulton - Making Solutions in Minutes for Limited Hand Function - A Make and Take Workshop cont.</td>
<td>Salon E</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Families through Adoption</td>
<td>Salon F</td>
<td>P</td>
</tr>
<tr>
<td>4:00 PM to 6:30 PM</td>
<td>Dinner on your own</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>6:30 PM to 9 PM</td>
<td>Prom</td>
<td>Salon DE</td>
<td>A</td>
</tr>
</tbody>
</table>

**Saturday, July 6, 2019**

<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>Salon DE</td>
<td>A</td>
</tr>
<tr>
<td>10 AM to 11:30 AM</td>
<td>Painting with Theresa, Face Painting with Chris</td>
<td>Salon GH</td>
<td>A</td>
</tr>
<tr>
<td>12 PM to 2 PM</td>
<td>Lunch on your own</td>
<td>On your own</td>
<td>A</td>
</tr>
<tr>
<td>2:00 PM to 2:45 PM</td>
<td>Annual Meeting, Closing Ceremony, Announcement of 2020 Location</td>
<td>Salon DE</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
- V – Volunteers
REACH FOR THE STARS

AMCers, Never Give Up! Keep Smiling Love, Jessica Lappin

Gabe the Babe, you are so amazing and so loved! We couldn’t be more proud of you! XOXO!!!

To our AMC Angels: There are some who bring a light so great to the world, when they are gone the light remains. Love you forever 💚

Dear Jessica, You continue to amaze us. Your family and friends are so proud of you!!! Keep going girl and Never give UP!!!!!

William - We are so very proud of you! Love, Mom, Dad, Jonathan and Rose

Dear Abby, Your Mom is a slacker and missed the deadline for the photo slideshow.

This is the next best thing! Love you! hahahaha! Love, Mom

Andrew: Never stop reaching for your dreams. The Tribe

Oliver we are so proud of your kindness, generosity, encouraging attitude, and perseverance. We love you all the way to the asteroid belt and back!!!

~Daddy & Mama
Women with Physical Disabilities Needed!

We are looking for women 18 years old or older to do online surveys and/or telephone interviews on topics related to:

- Managing periods
- Pregnancy
- Pelvic exams
- Communicating with health care providers

Compensation amount to be determined.
Contact us today for more information!

(734) 615-8543 | prowhd-research@umich.edu

UM Program for Research on Women’s Health and Disability (PROWHD)
To our Incredible DONORS (many of whom are anonymous) who contributed to this year’s Silent Auction, Children’s Programming, the Prom, and our Painting Sessions,

To our Wonderful VOLUNTEERS who gave up their energy and time to assist during this year’s Conference,

To our many other HELPERS and SUPPORTERS who step in when we need you,

Thank you for coming together to create an amazing experience at this year’s Conference!

We are so grateful for your help and support!
Providing multidisciplinary care for families of children living with AMC

- Orthopedic Surgery, Physical and Occupational Therapy and Orthotics – all under one roof
- Upper and Lower Extremity care provided
- Intensive Rehabilitation offered to attain goals and for post-operative care
- Proud to collaborate with AMCSI
- Strong network of family support of patients from all ages and stages
- Summertime occupational therapy camp for school age children
- Caring for children regardless of ability to pay

For an appointment, call
866.459.0013
No referral needed
www.GreenvilleShrinersHospital.org
David Feldman, MD
Director, Spinal Deformity Center

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.

Dr. Feldman is an expert in the care of AMC and related disorders. He has revolutionized the care of the Hip & Knee in this patient population, allowing for increased motion and better function.

Anastasia
Age 3 - Michigan
AMC Patient

901 45th Street
Kimmel Building
West Palm Beach, FL 33407
561-844-5255
www.paleyinstitute.org

WORLD RENOWNED CARE

Treating patients from over 90 countries, Dr. Feldman is a world-expert in the treatment of arthrogryposis.
BE SURE TO STOP BY AND SAY HI TO THE
AMC DADS

Get your copy of Valerie Pepe's autobiography
"Deformed: My Remarkable Life" in the Exhibitor Area!

WE NEED YOU!!!
Be a part of the first international research registry for adults with AMC. Your information will be anonymous and will help us learn more about living and aging with AMC.

Want to participate? Email Dr. Bonnie and say
"I want to participate in the registry"
Bonita.sawatzky@ubc.ca

The Planning Team
and Board of Directors of AMCSI
would like to thank the staff of the
Hilton Norfolk The Main
for their assistance in making the
14th Annual
Arthrogryposis Multiplex Congenita Support Conference
a huge success! We appreciate all of your
help and patience.

Thank you!!!

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

Providing free flights for patients in need of medical treatment far from home
215-358-1900
www.angelflighteast.org
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: 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.

Vice President: 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.

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, 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.
Secretary: 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 AMCer 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.

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.

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: Jennie Paradeis

Jennie Paradeis is a mom to 5-year-old AMPer daughter Dylann. She has a Master’s degree in counseling psychology and a Master's in Business Administration and currently works as a clinical consultant setting up behavioral health case management programs. Jennie lives in Minnesota with her husband Jeremy, son Micah, and Dylann and is excited to join the AMCSI Board of Directors and to continue advocating for those with AMC. In her free time, Jennie loves playing with the kiddos, traveling, going to the lake and cabins in the Minnesota summers, reading, and jogging.

TECHNOLOGY STAFF

Technical Director: Jeroen Tebbens

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.

Webmaster: Lori Carpenter

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 Masters 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. Maureen, Josy and Sean attended their first AMC Convention in Chicago and look forward to the AMC Conference every year.
**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 Team**

*Michele Schaffer: Vice President of Programming*  
*Ani Samargian: Founder*
Jean M 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 currently works for the Federal Government. After William’s birth, the Gephardt’s were overjoyed to find and join the AMCSI community. They 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 5-year-old AMCer named Brian and a 3-year-old named Coen. 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.

Beth Sellers: Director of Volunteers
Beth Sellers is a mom of four, including 12-year-old AMCer, Taylin. Beth is a graduate of James Madison University and Eastern Mennonite University with a Masters 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.

Jennifer Sander
Jen Sander is the proud mom of Emma and AMC angel, Isabel. Jen works at Aultman Hospital’s Birth Center as an OB/GYN registered nurse. She also works for Perry Local Schools as a school nurse. In her spare time, Jen enjoys being with her family and taking a much-needed nap. Jen and her family reside in Massillon, Ohio.
**Larina Swanson-Carter**
Larina and her amazing husband, Brian, have six children, Diamond, Jacob, Jade, Jaime, Oliver (AMC), and Tobin. Larina is a busy stay-at-home mama who is rarely actually home. In her free time, Larina enjoys camping, traveling, and crochet. Larina and her family reside in Black Earth, Wisconsin.

**Ana vanBosse**
Ana lives in the Philadelphia suburbs with her husband and two boys. She enjoys volunteer work in her kid's schools as well as Big Brothers Big Sisters, Philadelphia museum disabilities program and soup kitchen arts for the homeless. Before moving to Philly, she earned her MBA at St. John's University in NYC and worked for Verizon for 17 years at many different roles including Product Manager for Fios TV, Integration Manager for Verizon online, and Corporate Account Manager/Sales Engineer for major firms like IBM and Altria.

**Maureen Goede**

---

**PROM COMMITTEE**

Cherie Rice  Misha Walker  Carly Matthews

---

**PHOTOGRAPHY AND VIDEOGRAPHY**

Michelle Mockeridge  Alicia McCavanagh

Jessica Lappin  Michael Walker
Visit us online

www.amcsupport.org

Please follow & like us :)  
Facebook  www.facebook.com/AMCSUPPORT  
Twitter  https://twitter.com/amcsupport  
Instagram  https://www.instagram.com/amcsupport/  
Youtube  https://www.youtube.com/ (search for AMC Support)  
Gear up at the AMCSI Store: www.amcsupport.org/shop

Write, Email or Call
AMCSI
P.O. Box 6291
Spartanburg, SC 29304
amcsibod@gmail.com
1-805-55-AMCSI
(1-805-552-6274)

To the Loon Crew:
Ana, Ani, Beth, Betsy, Jean,
Jennifer, Larina, LaShell, & Maureen

You are an amazing group of talented women that I am not only lucky to call my friends, but privileged to witness first hand your talent and passion for AMCSI. Thank you for the endless hours you give to make this event a success! I couldn’t do it without you!

~ M

Recycle your outgrown orthotics. Send them to MD Orthopaedics / On His Path 604 N. Parkway Street Wayland, IA 52654

* A group of avian icons is legitimately called an Asylum! :)
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
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/minimeetups.html to look for a mini meet-up near you!
The Conference Planning Team would like to thank...

James Caron, Group Sales
Marriott Norfolk Waterside

Jayamary Michael
Division of Parking

Stephanie Peters
Program Animal Coordinator
Virginia Zoo

SOS Advertising
Conference T-Shirts

Karl Ehlers
Graphic Design

Hollywood Imprints Inc.
Planning Team Gear

Visit Norfolk

Vianetta Johnson, CMP, HMCC, Sales Manager
Jennifer Lopez, Convention Services Manager

Hilton Norfolk The Main
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
Rayven Hayes
Kali Pauline Heglmeier
Ian Hixson
Lainey Horning

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
Jedidiah Muñoz
E’zra Nelson
Jared Orner
Alexis Irellyn Pendak

Karrington Riley Reynolds
Caitlyn Rose Rout-Langdale
Isabel Sander
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 Arthrogryposis Center at the Shriners Hospitals for Children – Philadelphia supports the mission of the Arthrogryposis Multiplex Congenita Support, Inc, by providing and encouraging the understanding and support for those with arthrogryposis, as well as creating an awareness of AMC.

Drs. Harold van Bosse, Dan Zlotolow, Sarah Nossov and Scott Kozin 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 each child’s capabilities. And do so in a friendly, supportive and engaging space. The team’s ambition is to help their patients navigate the world as thriving independent adults.

For more information, please visit us at shrinersphilly.org, or to arrange to have your child seen, call 215.430.4140 or email us at PHLnewappts@Shrinenet.org.