Hilton Philadelphia at Penn’s Landing
Philadelphia, Pennsylvania, USA
September 24–26, 2018

3rd international symposium on arthrogryposis

Jointly Provided by: The International Study Group on Arthrogryposis and Lewis Katz School of Medicine at Temple University

PROGRAM

ENDORSED BY

POSNA
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AMCSI
WELCOME TO THE SYMPOSIUM

On behalf of planning committee, I welcome you to the 3rd International Symposium on Arthrogryposis, presented by the International Study Group on Arthrogryposis. This meeting has the distinction of being endorsed by both the Pediatric Orthopaedic Society of North America and the European Pediatric Orthopaedic Society, with generous underwriting from the Shriners Hospitals for Children. We have the privilege of having Professor Jaroslaw Czubak, the president of EPOS, and Richard Paula, MD, Chief Medical Informatics Officer for the Shriners Hospitals for Children, joining us as honored guests.

This meeting could not have been possible without the financial support and many hours of volunteerism of the Arthrogryposis Multiplex Congenita Support Inc., the largest arthrogryposis patient support group in North America, if not the world. The efforts of their all volunteer staff has contributed importantly to the style and functionality of the meeting. Continuing Medical Education credits are provided by the Lewis Katz School of Medicine at Temple University, underwritten by a generous grant from the Shriners Hospitals for Children.

At the end of this meeting, participants should be able to:

- Advance the treatment of children and adults with AMC
- Explain the advances of newer research and procedures/treatments that benefit peoples with AMC
- Advocate for the appropriate treatment of children born with AMC, by educating physicians and care givers of the potential of these children
- Describe the value of interdisciplinary care for these patients
- Foster an international community of physicians, care givers, researchers to further those goals

The purpose of our meeting will be both for scientific advancement and networking. From the scientific standpoint, we have more than 60 abstract podium presentations, 10 “Arthrogryposis Acumen” (2-minute presentations), and 10 didactic sessions. On our final day, Wednesday, there will be 6 different breakout sessions, where we hope to entice the attendees to actively participate, and harness the collective wisdom, experience and opinions of the group to develop a strategy going forward on these varied topics. For some topics, we hope to have enough material to produce an “Expert Opinion Letter”. For other
topics, the sessions will serve as a foundation for further research. In all cases, we hope to find motivated parties to continue working as a group after the meeting has concluded.

As for networking, we hope to encourage both informal as well as formal interactions, to foster research collaborations. On Monday night, the International Study Group for Arthrogryposis will host the meeting dinner, to which all registered participants are invited to attend!

This scientific meeting will follow the structure of contemporary scientific meetings, based primarily on podium presentations of research abstracts. The abstracts were chosen based on the quality of information presented and relevance for the treatment of patients with AMC.

The planning committee is very proud of the program created. This 3rd International Symposium on Arthrogryposis follows the 1st Symposium in Birmingham, UK, in 2007, organized by Dr. Ruth Lester, and the 2nd Symposium held in 2014 in Saint Petersburg, Russia, organized by Dr. Olga Agranovich. It was an honor to have both Drs. Lester and Agranovich as active members of this 3rd Symposium’s planning committee. Furthermore, we are excited that the momentum continues, with the announcement that the 4th International Symposium on Arthrogryposis will occur in Montreal, Canada in 2021!

Harold J. P. van Bosse
President, International Study Group on Arthrogryposis
Chair, Planning Committee, 3rd International Symposium on Arthrogryposis
LANGUAGE
English will be the official language of the International Symposium.

NO SMOKING POLICY
Smoking is not permitted during any meeting or event.

NO CAMERAS OR VIDEO CAMERAS
Cameras or video cameras may not be used in any portion of the scientific session.

NO REPRODUCTIONS
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INTERNET
Free wireless internet available in the lobby of the hotel, ground floor.
SYMPOSIUM PLANNING COMMITTEE

- **Harold van Bosse, MD**, Chair, 3rd International Symposium on Arthrogryposis
- Shriners Hospital for Children, Philadelphia, Pennsylvania USA
- Birmingham Children’s Hospital NHS Foundation Trust, Birmingham, England
- **Olga Agranovich, MD**, Organizer of the 2nd International Symposium on Arthrogryposis, 2014
- Turner Scientific and Research Institute for Children’s Orthopedics, Saint-Petersburg, Russia
- **Michele Cimino, MSN RN**, Manager of Education and Development, Shriners Hospital for Children, Philadelphia, Pennsylvania USA
- **Judith Hall, MD** - British Columbia’s Children’s Hospital, Vancouver, British Columbia Canada
- **Chris Hartwick**, President, Arthrogryposis Multiplex Congenita Support, Inc Greenville, South Carolina USA
- **Bartłomiej (Bart) Kowalczyk, MD PhD**, Organizer of the International Interdisciplinary Conference on Arthrogryposis -University Children Hospital of Krakow, Poland
- **Noémi Dahan-Oliel, PhD, OT** - Shriners Hospitals for Children-Canada and McGill University, Montréal, Québec Canada
- **Eva Pontén, MD** - Karolinska University Hospital, Stockholm, Sweden
- **Ani Samargian, Founder**, Arthrogryposis Multiplex Congenita Support, Inc Spartanburg, South Carolina USA
- **Michele Schaffer**, Vice President for Programming, Arthrogryposis Multiplex Congenita Support, Inc., Columbus, Ohio USA
- **Albert Weiss, MD**, Shriners Hospital for Children, Philadelphia, Pennsylvania USA
- **Dan Zlotolow, MD**, Shriners Hospital for Children, Philadelphia, Pennsylvania USA
**SUBCOMMITTEES**

**Genetics and Related Issues**
- Judith Hall, MD, lead
- Klaus Dieterich, MD
- Philip Giampietro, MD

**Lower Extremity**
- Bartłomiej Kowalczyk, MD PhD, lead
- L. Reid Boyce Nichols, MD
- Sarah Nossov, MD
- Eva Pontén, MD
- Harold van Bosse, MD
- Akifusa Wada, MD

**Orthotics**
- Eva Pontén, MD, lead
- Calli Clark, CPO
- Marie Eriksson, CPO, PhD
- Monika Wojciechowska, PT

**Rehabilitation**
- Maureen Donohoe, PT, DPT, PCS, lead
- Suzanne Cherry, PT, DPT, PCS
- Caroline Elfassy, OT
- Heather Ford, OT
- Unni Steen, OT MSc
- Lisa Wagner, DHS, OTR/L

**Research**
- Noémi Dahan-Oliel, PhD, lead
- Bonita Sawatzky, PhD

**Upper Extremity**
- Dan Zlotolow, MD, lead
- Olga Agranovich, MD
- Andrea Jester, MD
- Scott Oishi, MD

**MEETING LOGISTICS TEAM**
- Don Bahr – Public relations, Arthrogryposis Multiplex Congenita Support, Inc
- Jean Balent-Gephardt – Audio-visual technologies
- Michele Cimino – Continuing Medical Education coordinator
- Chris Hartwick – Printed material developer
- Jared Kampf - Symposium treasurer
- Alicia McCavanagh – Official Symposium photographer
- Brian O’Doherty – Visual media
- Alexis Record - Delegate facilitator
- Ani Samargian – Meeting facilitator and logistics
- Michele Schaffer - Hotel relations
- Misha Walker - International Ambassador, Arthrogryposis Multiplex Congenita Support, Inc
- Albert Weiss – Commercial vendor/sponsor relations
ACKNOWLEDGEMENTS AND GRATITUDE

- Tanya N. Baker, CMP, Director, Global Accounts HelmsBriscoe
- Kerry Fledderman, HMMC, Sales Manager, and Jasmine Laraichi, Convention Services Manager, Hilton Philadelphia at Penn’s Landing
- Matt Juliano, Director, and Paul Wermuth, Sales Manager, PSAV
- Elizabeth M. Oquendo, JD, Director and Arnold I. Meyer Ed.D., FACEHP, Associate Director, COI and CME, Lewis Katz School of Medicine, Temple University
- Marty Sheedy, Project Scissor Gait Foundation

The International Study Group for Arthrogryposis gratefully acknowledges The Shriners Hospitals for Children for financing the Continuing Medical Education (CME) credits, provided through Temple University Lewis Katz School of Medicine.

Most importantly, the International Study Group for Arthrogryposis extends its deep appreciation to Arthrogryposis Multiplex Congenita Support, Inc (AMCSI) for financially underwriting this conference.
SPONSORS & EXHIBITORS

The International Study Group on Arthrogryposis thanks the following entities for their generous support and exhibits:

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Michele Schafffer
Cheryl Schalk
Theresa Tamash

EXHIBITOR SUPPORT
Shriners Hospital for Children Montreal and Shriners Hospital for Children Philadelphia
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AGENDA

MONDAY SEPTEMBER 24, 2018 (6.75 CME) (408 MINUTES)

7:00 am to 8:00 am  Breakfast/Registration

8:00 am to 8:20 am  Welcome/Housekeeping

8:20 am to 10:31 am  Scientific Sessions (130 minutes)

8:20 am-9:05 am  Genetics Didactic Session (45 minutes)
Moderator – Judith Hall
- Introduction— Clinical Approach — Judith Hall
- Amyoplasia Update — Judith Hall
- Distal Arthrogryposis with Emphasis on Intra-familial Variability— Eva Kimber
- Neurologic Forms of Arthrogryposis— Klaus Dieterich
- Questions

9:06 am-10:05 am  Upper Extremity Abstracts, Elbow (60 minutes)
Moderator – Alice Chu

9:06 am-9:12 am  Results and Functional Assessment of Long Head Triceps Transfer in Four Children with Arthrogryposis
Bart Kowalczyk, Fąfara Alicja

9:13 am-9:19 am  Free Functional Muscle Transfer for Reanimation of Elbow Flexion in Children with Arthrogryposis
Vinay N. Itte, Robert D. Bains, Grainne Bourke, Simon P.J. Kay

9:20 am-9:26 am  Our Approach for Reconstruction of Active Elbow Flexion in Children with Amyoplasia
Olga Agranovich, Ekaterina Petrova, Svetlana Trofimova, Dmitry Buklaev, Evgenia Kochenova

9:27 am-9:35 am  Discussion

9:36 am-9:42 am  Functional Improvement After Posterior Elbow Release in Arthrogrypotic Children
Alicja Fąfara, Kowalczyk Bart
9:43 am-9:49 am  Elbow Release and Tricepsplasty in Arthrogrypotic Patients- A Long Term Follow Up Study
**Paper #5**
Christopher Stutz, Jue Cao, Anna Browing, Terri Beckwith, Scott N. Oishi

9:50 am-9:56 am  Outcome of Thumb in Palm Surgery in Children with Arthrogryposis
**Paper #6**
Andrea Anna Maria Jester, Kerstin Oestreich, Laura Sunderland, Ruth Lester

9:57 am-10:05 am  Discussion

10:06 am-10:31 am  **Rehabilitation Didactic Session (25 minutes)**
Moderator - Maureen Donohoe
- OT: Enhancing ADL Performance:
  - Adaptive Equipment to Enhance the Abilities - Heather Ford
  - Adult Perspective for ADL and Adaptive Equipment - Unni Steen
  - Case Presentations - Caroline Elfassy
- Discussion

10:32 am-10:52 am  Coffee Break (25 minutes)

10:52 am-12:29 pm  Scientific Sessions (90 minutes)

10:52 am-11:51 am  **Lower Extremity Abstracts, Hips and Clubfeet (60 minutes)**
Moderator – David S. Feldman

10:52 am-10:58 am  Does Open Reduction of Arthrogrypotic Hips Cause Stiffness?
**Paper #7**
Harold J.P. van Bosse

10:59 am-11:05 am  Reorientational Proximal Femoral Osteotomies for Arthrogrypotic Hip Contractures
**Paper #8**
Harold J.P. van Bosse, Roger E. Saldana

11:06 am-11:12 am  A Long-term Outcome After Surgeries for Lower Limbs in Children with AMC
**Paper #9**
Toru Yamaguchi, Akifusa Wada, Tomoyuki Nakamura, Kazuyuki Takamura, Haruhisa Yanagida, Toshio Fujii

11:13 am-11:21 am  Discussion
11:22 am-11:28 am  Paper #10  Pirani Scores Better Demonstrate Clinical Change in Idiopathic and Non-idiopathic Clubfoot
Sarah B. Nossov, John Gaughan PhD, Nikki Sutliff, Harold J.P. van Bosse

11:29 am-11:35 am  Paper #11  Orthopaedic Scientific Literature Has Poor Uniformity in Defining Clubfoot Relapse
Dayna M. Phillips, Cheryl Lawing, Sarah B. Nossov

11:36 am-11:42 am  Paper #12  Effectiveness of the Ponseti Method in Treating Foot Deformities in Children with Arthrogryposis
Daveda Taylor, Chris F. Church, Nancy Lennon, John Henley, Maureen Donohoe, L. Reid Nichols

11:43 am-11:51 am  Discussion

11:52 pm-12:22 pm  Upper Extremity Didactic Session (30 minutes)
Moderator - Dan Zlotolow
• Humeral Osteotomy
  - Crossover Grasp Is Good – Michelle James
  - Crossover Is No Longer Acceptable – Lindley Wall
  - Discussion 5 min
• Elbow Flexorplasties
  - Passive Motion Is Best – Michelle James
  - Active Motion Is Better – Scott Oishi
  - Discussion

12:22 pm-1:25 pm  Lunch (on own) (60 minutes)

1:25 pm-2:55 pm  Scientific Sessions (90 minutes)

1:25 pm-1:55 pm  Lower Extremity Didactic Session (30 minutes)
Moderator - L. Reid Nichols
• Early Clubfoot Treatment - What to Do with Persistent Deformity After Initial Casting: Achilles Tenotomy and Prolonged Casting Versus Early Limited Surgical Release? L. Reid Nichols and Bart Kowalczyk
• When to Release Knee Extension Contractures: at Early Age or Delay Until Later? Eva Pontén and Akifusa Wada
• Discussion and Conclusions
1:56 pm-2:55 pm  **Outcomes Research Abstracts, Quality of Life and Participation (60 minutes)**
Moderator - Noémi Dahan-Oliel

1:56 pm-2:02 pm  Patient Reported Outcomes Measurement

**Paper #13**
Information System (PROMIS) Scores for Children with AMC
Michelle A. James, Nancy Abarca, M. Claire Manske

2:03 pm-2:09 pm  Patient Reported Outcomes in Arthrogryposis

**Paper #14**
Lindley Wall, Charles A Goldfarb, Summer Roberts, Donald S. Bae, Carley Vuillermin, CoULD Registry

2:10 pm-2:16 pm  Participation Among Children and Youth with Arthrogryposis Multiplex Congenita: A Scoping Review
Caroline Elfassy, Sarah Cachecho, Laurie Snider, Noémi Dahan-Oliel

2:17 pm-2:25 pm  Discussion

2:26 pm-2:32 pm  Using the Oswestry Disability Index for Pain and Disability in Arthrogryposis Multiplex Congenita
Bonita J Sawatzky, Rebecca Miller, Talon Jones, John Street

2:33 pm-2:39 pm  Long-term Follow Up on Quality of Life and Function of Adults with Arthrogryposis
Haluk Altiok, Ann Flanagan, Joseph J. Krzak, Sahar Hassani

2:40 pm-2:46 pm  Compensatory Strategies for Performing Activities of Daily Living in Adults with Amyoplasia
Unni E. Steen, Lena L. Wekre

2:47 pm-2:55 pm  Discussion

2:55 pm-3:15 pm  Coffee Break (20 minutes)

3:15 pm-4:53 pm  Scientific Sessions (98 minutes)

3:15 pm-3:44pm  **Genetics Abstracts (30 minutes)**
Moderator - Philip Giampietro

3:15 pm – 3:21 pm  Muscle MRI in Amyoplasia: Diagnostic Biomarker and Further Evidence for a Motor Neuron Disease
Klaus Dieterich, Hoai Thu Nguyen, Chantal Durand, Caroline du Bois, Pierre-Simon Jouk
3:22 pm-3:28 pm  Arthrogryposis - Genetic Update  
**Paper #20**  
Judith G. Hall, Jeff Kiefer  

3:29 pm-3:35 pm  Natural Progression of Orthopedic Deformities in Bruck Syndrome  
**Paper #21**  
Richard Kruse, Jeanne Franzone, Michael Bober, Reid Nichols, Geovanny Oleas-Santillán, Richard Bowen  

3:36 pm-3:44 pm  Discussion  

3:45 pm-4:53 pm  **Outcomes Research Abstracts (68 minutes)**  
Moderator - Noémi Dahan-Oliel  

3:45 pm-3:51 pm  Defining AMC: Towards a Consensus on Terminology  
**Paper #22**  
Sarah Cachecho, Caroline Elfassy, Peter Rosenbaum, Reggie Hamdy, Noémi Dahan-Oliel  

3:52 pm-3:58 pm  An Initial Report on a Grading System for Global Assessment of the Child with Amyoplasia  
**Paper #23**  
Bart Kowalczyk, Anna Kuźnik-Buziewicz, Alicja Fąfara, Bogusława Banaś  

3:59 pm-4:05 pm  Relationship of Ambulatory Function Based on Infantile Lower Extremity Posture Types in Amyoplasia  
**Paper #24**  
Maureen Donohoe, Blazej Pruszcynski, Kenneth Rogers, James Richard Bowen  

4:06 pm-4:12 pm  Disability in Adults with Arthrogryposis Is Severe, Partly Invisible, and Varies by Genotype  
**Paper #25**  
Louis Dai, Klaus Dieterich, Marie Jaeger, Pierre-Simon Jouk, Dominique Perennou  

4:13 pm-4:21 pm  Discussion  

4:22 pm-4:28 pm  Functional Outcomes Among Children with AMC: Retrospective Review on 114 Charts  
**Paper #26**  
Klaus Dieterich, Louis Dai, Marie Jaeger, Pierre-Simon Jouk, Dominique Perennou, Noémi Dahan-Oliel, Reggie Hamdy, Caroline Elfassy, Kathleen Montpetit, Delphine Hansen-Jaumard
4:29 pm-4:35 pm  Health-related Quality of Life and Orthosis Use in a Swedish Population with Arthrogryposis
Paper #27
Marie Eriksson, Li Villard, Anna-Karin Kroksmark, Åsa Bartonek

4:36 pm-4:44 pm  Preliminary Report on a Method of Assessing Functional Hip Motion
Paper #28
Harold J. P. van Bosse, Justin San Juan, Solomon Praveen Samuel

4:45 pm-4:53 pm  Discussion

5:00 pm  Adjournment

6:00 pm-9:00 pm  International Study Group for Arthrogryposis Dinner

6:00 pm-7:00 pm  Cocktail hour, Columbus Ballroom Foyer
7:00 pm-9:00 pm  Dinner, Columbus Ballroom, 2nd Floor, Hilton Philadelphia at Penn’s Landing

TUESDAY, SEPTEMBER 25, 2018 (7.75 CME) (470 MINUTES)

7:00 am to 8:00 am  Breakfast/Registration

8:00 am to 8:15 am  Welcome/Housekeeping

8:15 am to 10:10 am  Scientific Sessions (115 minutes)

8:15 am – 8:40 am  Rehabilitation Didactic Session (25 minutes)
Moderator - Lisa Wagner
PT: Mobility
• Early Gait Trainer Use Versus Balance in Braces: Is Walking or Standing Balance the Priority? - Maureen Donohoe
• Strategies for Progressive Ambulation Using Partial Weight Bearing Support - Suzanne Cherry
• Mobility for Long Distances: Walking Versus Wheelchair - Chris Church
• Discussion with Audience
8:41 am-9:10 am  | **Research Abstracts, Registries (30 minutes)**
Moderator - Kathleen Montpetit

8:41 am-8:47 am  | Outcomes of Adults with Arthrogryposis Multiplex Congenita
**Paper #29**
Bonita Sawatzky, Hirmand Nouraei

8:48 am-8:54 am  | Arthrogryposis Multiplex Congenita: A Multi-site Pilot Registry in Pediatrics
**Paper #30**
Noémi Dahan-Oliel, Tanya Bedard, Vasiliki Darsaklis, Judith G. Hall, Harold J.P. van Bosse, Reggie Hamdy

8:55 am-9:01 am  | The Creation of an Adult Arthrogryposis Research Registry
**Paper #31**
Bonita J Sawatzky, Shweta Yadav, Ann Marie Davison, Patricia Mills, Noémi Dahan-Oliel

9:02 am-9:10 am  | Discussion

9:11 am-10:10 am  | **Lower Extremity Abstracts, Foot Deformities (60 minutes)**
Moderator – David S. Feldman

9:11 am-9:17 am  | Conception of Achilles Tenotomy in Children with Arthrogryposis
**Paper #32**
Svetlana Trofimova, Olga Agranovich, Denis Derevyanko

9:18 am-9:24 am  | Treatment of Arthrogrypotic Clubfeet Using Ponseti Casts and Posterior Ankle Release
**Paper #33**
Bart Kowalczyk, Anna Kuźnik

9:25 am-9:31 am  | Longitudinal Management of Recurrent Arthrogrypotic Clubfeet with Ponseti Management
**Paper #34**
Sarah B. Nossov, Justin San Juan, Nikki Sutliff, Harold J.P. van Bosse MD

9:32 am-9:40 am  | Discussion

9:41 am-9:47 am  | Identifying Equinocavus Variant of Arthrogrypotic Clubfoot
**Paper #35**
Sarah B. Nossov, Nikki Sutliff, Harold J.P. van Bosse

9:48 am-9:54 am  | Treatment Severe Deformities of Plano-valgus Feet in Children with Arthrogryposis
**Paper #36**
Ekaterina Petrova, Svetlana Trofimova, Dmitrii Buclaev, Evgenia Kochenova
9:55 am-10:01 am  Reducing Recurrence of Equinus in Tibial Dorsiflexion Osteotomies by Tendon Transfer and Wolff's Law

**Paper #37**
Hari Prem

10:02 am-10:10 am  Discussion

10:10 am-10:30 am  Coffee Break (20 minutes)

10:30 am-12:55 pm  Scientific Sessions (110 minutes)

10:30 am-10:50 am  **Orthotics Didactic Session (20 minutes)**
Moderator - Eva Pontén

- Overview of Orthoses to Enable or Improve Walking and Use of Different Materials Such as Thermoplastics and Carbon Fiber - Marie Eriksson
- Design and Use of KAFOs to Control Deformity and Enhance Function and AFOs to Control Clubfoot Relapse - Calli Clark
- Orthoses for Thumb, Wrist and Elbow. AFOs for Walking, and to Prevent Club Foot Relapse - Monika Wojciechowska
- Spine orthoses - Michał Gutswa

10:51 am-11:20 am  **Multidisciplinary Clinics Abstracts (30 minutes)**
Moderator - Maureen Donohoe

10:51 am-10:57 am  An AMC Multidisciplinary Clinic: Using the COPM to Ensure a Family-centered Model of Care

**Paper #38**
Emily Lecker, Reggie Hamdy, Chantal Janelle, Kelly Thorstad, Noémi Dahan-Oliel

10:58 am-11:04 am  AMC Patient Management at the University Hospital Grenoble/ France: a Single Center Experience

**Paper #39**
Klaus Dieterich, Gipsy Billy, Véronique Bourg BOURG, Dominique Perennou, Pierre-Simon Jouk

11:05 am-11:11 am  The Development of an MDT Approach to Arthrogryposis at Birmingham Children’s Hospital

**Paper #40**
Andrea Jester, Kerstin Oestreich, Ruth Lester

11:12 am-11:20 am  Discussion
11:21 am-11:50 am  **Lower Extremity Abstracts, Gait** *(30 minutes)*
Moderator - TBA

**Paper #41**
Foot Deformities and Gait Deviations in Children
with Arthrogryposis
Daveda Taylor, Chris F. Church, Nancy Lennon,
Michael W. Shrader, Maureen Donohoe, L. Reid Nichols

11:28 am-11:34 am  **Paper #42**
AFO with Dynamic Carbon Fibers Improves Selected
Gait Parameters in Children with Arthrogryposis
Monika Wojciechowski, Bart Kowalczyk, Michał Gutswa, Krzysztof Krasowicz

11:35 am-11:41 am  **Paper #43**
Less Invasive Treatment of the Lower Limb and
Carbon Fiber Spring Orthoses May Improve Gait in AMC
Eva M Pontén, Marie Eriksson

11:42 am-11:50 am  Discussion

11:51 am-12:20 pm  **Upper Extremity Abstracts, Wrist** *(30 minutes)*
Moderator – Jennifer Ty

**Paper #44**
Growth Modulation for Recurrent Flexion Deformity
in Arthrogryposis
Scott N. Oishi, Christopher Stutz, Terri Beckwith, Anna Browning

**Paper #45**
Comparison for Techniques of Treatment of Wrist
Flexion Deformity in Arthrogryposis
Hisham Abdel-Ghani, Mahmoud Mostafa, Hosam Amin

12:05 am –12:11 pm  **Paper #46**
Wrist Contractures in Children with AMC: Long-
term Follow Up of Surgical Treatment
Evgeniia Kochenova, Olga Agranovich

12:12 pm-12:20 pm  Discussion

12:20 pm-1:20 pm  Lunch (on own) *(60 minutes)*

1:20 pm-3:40 pm  **Scientific Sessions** *(140 minutes)*
1:20 pm-1:50 pm  **Genetics Didactic Session** *(30 minutes)*  
Moderator – Judith Hall  
- Introduction — Importance of a Specific Diagnosis  
- Genetic Workup— Philip Giampietro  

1:51 pm-2:50 pm  **Lower Extremity Abstracts, Knee** *(60 minutes)*  
Moderator – Akifusa Wada  
1:51 pm-1:57 pm  Guided Growth for Knee Flexion in Arthrogryposis:  
**Paper #47**  
Neurovascular Encroaching with Bone Funnelization  
Geovanny Oleas Santillán, Richard Bowen  
1:58 pm-2:04 pm  Guided Growth with Hinge Tension Band Plate for  
**Paper #48**  
Lack Of Extension of the Knee in Arthrogryposis  
Miguel A. Galban, Adolfredo Santana  
2:05 pm-2:11 pm  Correction of Mild to Moderate Arthrogrypotic Knee  
**Paper #49**  
Flexion Contractures with Guided Growth  
Harold J.P. van Bosse  
2:12 pm-2:20 pm  Discussion  
2:21 pm-2:27 pm  Improving Knee Range of Motion in Arthrogrypotic Knee  
**Paper #50**  
Knee  
David Feldman, Erica Boliek, Troy Rand, Aaron Huser  
2:28 pm-2:34 pm  Treatment of Severe Knee Flexion Contractures in  
**Paper #51**  
Patients with Arthrogryposis  
Harold J.P. van Bosse  
2:35 pm-2:41 pm  Delayed Surgery in Amyoplasia-Does it Work?  
**Paper #52**  
Andreas Knaus  
2:42 pm-2:50 pm  Discussion  

2:51 pm-3:40 pm  **Upper Extremity Didactic Session** *(50 minutes)*  
Moderator – Michelle James  
- Carpal Wedges  
  - When and Why I Do Them - Scott Oishi  
  - When and Why I don’t – Max Horowitz  
  - Discussion
- Thumb in Palm
  - When and How to Reconstruct - Dan Zlotolow
  - When to Leave Alone - Andrea Jester
- Discussion

3:40pm-4:00pm  Coffee Break (20 minutes)
4:00 pm-5:44 pm  Scientific Sessions (105 minutes)

4:00 pm-5:00 pm  Research Didactic Session (60 minutes)
Outcome Measures for Children and Adults with Arthrogryposis: Challenges in Clinical and Research Use
Moderator - Noémi Dahan-Oliel
- Patient Reported Outcome, and the Use of the PODCI: Specific Objective Outcomes Looking at Grasp Patterns - Lindley Wall
- Health Related Quality of Life and Health Status, Functional Capabilities, and Satisfaction with Orthosis and Gait Analysis - Marie Eriksson
- Outcomes, Function, and Quality of Life in Adults with AMC - Haluk Altiok
- International Survey of 150+ Adults with AMC, Using Self-report - Bonnie Sawatzky
- Panel Discussion

5:01 pm-5:44 pm  Arthrogryposis Acumen (45 minutes)
Moderator - Harold van Bosse
5:01 pm-5:03pm  Introduction
5:03 pm-5:05pm  External Tibial Torsion Accompanying Arthrogrypotic Clubfoot Deformities – Harold van Bosse
5:05 pm-5:07 pm  The Power of the Wedge – Harold van Bosse
5:08 pm-5:10 pm  Standing Balance: the Art of the Shoe Wedge – Maureen Donohoe
5:11 pm-5:13 pm  Prediction of Ambulation – Maureen Donohoe
5:14 pm-5:16 pm  Lower Limb Amyoplasia Presenting with Severe Scoliosis and Unusual Skin Dimpling – Ted Matthew Padilla Evangelista
5:17 pm-5:23 pm  Discussion
Maintaining a Delicate Balance – Michelle James
Tendon Transfer in the Arthrogrypotic Thumb – Giorgio Pajardi
The Thumb in AMC - Dan Zlotolow
Does Age Matter - Dan Zlotolow
Child Life Services – Jessie Smith
Discussion
Adjournment

WEDNESDAY, SEPTEMBER 26, 2018 (5.0 CME)

7:00 am to 8:00 am Breakfast/Registration

8:00 am to 8:10 am Welcome/Housekeeping

8:10 am to 10:35 am Scientific Sessions (143 minutes)

8:10 am-8:55 am Lower Extremity Didactic Session (45 minutes)
Moderator - Eva Pontén

- Is Talectomy Still a Valuable Option for Arthrogrypotic Clubfeet Or it Is Out of Use, Replaced by Supramalleolar Osteotomies, Triple Arthrodesis or Frames?
  L. Reid Nichols and Harold van Bosse
- Knee Flexion Contractures Treatment: Guided Growth Versus Posterior Releases for Mild Contractures?
  Eva Pontén and Bart Kowalczyk
  Harold van Bosse and Akifusa Wada

8:56 am-9:46 pm Upper Extremity Abstracts, Miscellaneous (50 minutes)
Moderator - Giorgio Pajardi

8:56 am-9:02 am Pioneering Wrist Arthroscopy in a Patient with Arthrogryposis
Paper #53
Andrea Jester, Jeanette Ting, Janak A. Bechar, Laura Sunderland, Tommy Lindau, Kirstin Oestreich
9:03 am-9:09 am  Effects of the Playskin LiftTM Exoskeletal Garment on Arm Function for Children with Arthrogryposis
Paper #54  Iryna Babik, Andrea B. Cunha, Michele A. Lobo

9:10 am-9:16 am  Discussion

9:17 am-9:23 am  Sensory Modulation and Emotional Regulation in Posterior Capsular Elbow Release Patients
Paper #55  Heather Rose Ford, Jacqueline Macri

9:24 am-9:30 am  Patient and Parent Satisfaction after Upper Limb Surgery
Paper #56  Andrea Anna Maria Jester, Kerstin Oestreich, Laura Sunderland, Ruth Lester

9:31 am-9:37 am  An Upper Extremity Evaluation Tool for Children with Arthrogryposis Multiplex Congenita
Paper #57  Caroline Elfassy, Lisa Wagner, Laurie Snider, Nathalie Bilodeau, Cynthia Gagnon, Noémi Dahan-Olivel

9:38 am-9:46 am  Discussion

9:47 am-10:35 am  Rehabilitation Needs and Spine (48 minutes)
Moderator - Suzanne Cherry

9:47 am-9:53 am  Rehabilitation Needs in Arthrogryposis Multiplex Congenita: Multiple Stakeholder Perspectives
Paper #58  Caroline Elfassy, Noémi Dahan-Olivel, Vasiliki Darsaklis, Laurie Snider, Cynthia Gagnon, Reggie Hamdy

9:54 am-10:00 am  Towards the Development of Best Practice Guidelines for Rehabilitation
Paper #59  Noémi Dahan-Olivel, Kathleen Montpetit, Cristina Patulli, Lisa Wagner, Maureen Donohoe, Reggie Hamdy

10:01 am-10:07 am  Measuring Efficacy of Physical Rehabilitation in Children and Adults with Arthrogryposis
Paper #60  Maureen Donohoe

10:08 am-10:16 am  Discussion

10:17 am-10:23 am  Serial Derotational Spinal Casting in Early Onset Scoliosis Secondary to Arthrogryposis Multiplex Congenita
Paper #61  Harold J. P. van Bosse, Brandon J. Toll
10:24 am-10:30 am  Magnetically Controlled Growing Rods in Scoliosis

**Paper #62**

Secondary to Arthrogryposis Multiplex
Harold J.P. van Bosse, Brandon J. Toll, Joshua M. Pahys, Steven W. Hwang, Amer F. Samdani

10:31 am-10:35 am  Discussion

10:35 am-11:00 am  Coffee Break (25 minutes)

11:00 am-11:50 am  Breakout Sessions (50 minutes)
  - Outcomes Evaluations – Maureen Donohoe and Lisa Wagner, facilitators
  - Standard of Care Guidelines – Klaus Dieterich, facilitator

12:00 pm-12:50 pm  Breakout Sessions (50 minutes)
  - Pre-natal Diagnosis – Judith Hall, Philip Giampietro and Kerby Oberg, facilitators
  - Rehab guidelines - Noémi Dahan-Oliell and Kathleen Montpetit, facilitators

1:00 pm-1:50 pm  Breakout Sessions (50 minutes)
  - Classification Systems - Judith Hall and Kerby Oberg, facilitators
  - Discussion session with non-medical participants – Ani Samargian and Misha Walker, facilitators

1:50 pm-2:00 pm  Closing Remarks/Evaluations

Summary of breakout sessions
Promoting a greater overall understanding and awareness of arthrogryposis multiplex congenita (AMC)—as a resource not only for the membership, but for the general public and those in the field of medicine and research.

Conferences—family and medical support
Grants—adoption, college, research
Mini Meets—regional meetings
local meetups

Proud sponsor of the 3rd International Symposium on Arthrogryposis
The Mission of Roger’s Run 4 AMC is to increase awareness of Arthrogryposis Multiplex Congenita (AMC) through the promotion and encouragement of distance running and walking. Toward this end Rogers Run 4 AMC promotes an annual 5K run, 5K walk, and 1 mile run.

The Vision of Roger’s Run 4 AMC is to promote a climate of understanding with regard to AMC and decrease the level of hardship faced by families impacted by AMC.
Run for Jack is a charity event whose mission is to raise awareness and support for those with Arthrogryposis Multiplex Congenita (AMC). Additionally, the event engages the community in a fun event through a 5k run, one-mile walk and kids fun run. All proceeds are donated to the Arthrogryposis Support Group.
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We are proud to offer our top notch care and support for the AMC community under the leadership of Drs. Harold van Bosse, Scott Kozin, Dan Zlotolow, and Sarah Nossov.

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In Canada, Shriners Hospitals for Children offer the only multi-disciplinary team approach to help children and families who are living with arthrogryposis.

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Dylann’s Dash is an annual charity 5K event whose mission is to raise money for the non-profit organization, Arthrogryposis Multiplex Congenita Support, Inc. (AMCSI), in an effort to continue to raise awareness and support for those with arthrogryposis in addition to the following:

• Increase awareness and overall understanding in the state of Minnesota for the condition called Arthrogryposis Multiplex Congenita (AMC) for both individuals and families of those with the condition but also the medical professionals and general populations
• Provide support to individuals and families with AMC
• Provide financial assistance to individuals and families with AMC as well as scholarship assistance to college students who are going into the field of orthopedics or physical therapy, and plan to include AMC as their area of study
• Contribute financially to AMCSI and other organizations who support and treat those with AMC

For more information write to dylannsdash@yahoo.com or visit us at dylannsdash.com
The International Study Group for Arthrogryposis thanks

Dawn Dame
for the contribution to the 3ISA

Susan Henderson
for the contribution to the 3ISA

Valerie Pepe
for the contribution to the 3ISA

Michele Schaffer
for the contribution to the 3ISA

Cheryl Schalk
for the contribution to the 3ISA

Theresa Tamash
for the contribution to the 3ISA
Looking forward to our next symposium

Montreal

2021
Arthrogryposis
Day
June 30th
Celebrate!
let's celebrate!
Arthrogryposis
AMC Strong
Awareness Day
AMCSI
Arthrogryposis Multiplex Congenita Support, Inc.
Join us for our

14th Annual
Arthrogryposis Multiplex Congenita
Support, Inc. Conference
Norfolk, Virginia
July 3-6, 2019

We hope that you can join us for the Annual AMCSI Conference which provides an opportunity for people affected by arthrogryposis multiplex congenita to gather and exchange ideas and support. During the three-day event, families and medical professionals participate in a variety of sessions and children’s activities providing different kinds of information to meet the needs of our ever-growing AMC family. Our planning committee is reaching out to medical professionals and speakers from around the country. Would you be interested in being a speaker?

Arthrogryposis Multiplex Congenita Support, Inc., started as an online support forum; therefore, we believe that these support sessions are just as important as those that offer medical information. Watch for our notices on Facebook and our website in early spring.

For more information visit us at amcsupport.org