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 (12 minutes)
Distal Arthrogryposis with Emphasis on Intrafamilial Variability—Eva Kimber (12 minutes)
Neurologic Forms of Arthrogryposis—Klaus Dieterich (12 minutes)
Questions (9 minutes)

9:06 am-10:05 am Upper Extremity Abstracts, Elbow (60 minutes)
9:06 am-9:12 am Results and Functional Assessment of Long Head Triceps Transfer in Four Children with Arthrogryposis
Bart Kowalczyk, Fařara 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 Fařara, Kowalczyk Bart
9:43 am-9:49 am Elbow Release and Tricepsplasty in Arthrogrypotic Patients- A Long Term Follow Up Study
Christopher Stutz, Jue Cao, Anna Browning, Terri Beckwith, Scott N. Oishi
9:50 am-9:56 am Outcome of Thumb in Palm Surgery in Children with Arthrogryposis
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)
OT: Enhancing ADL Performance:
1. Adaptive Equipment to Enhance the Abilities - Heather Ford
2. Adult Perspective for ADL and adaptive equipment - Unni Steen
3. Case Presentations - Caroline Elfassy
4. Discussion with Audience

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)
10:52 am-10:58 am Does Open Reduction of Arthrogrypotic Hips Cause Stiffness?
Harold Jacob Pieter van Bosse
10:59 am-11:05 am Reorientational Proximal Femoral Osteotomies for Arthrogrypotic Hip Contractures
Harold Jacob Pieter van Bosse, Roger E. Saldana
11:06 am-11:12 am A Long-term Outcome After Surgeries for Lower Limbs in Children with AMC
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  **Pirani Scores Better Demonstrate Clinical Change in Idiopathic and Non-idiopathic Clubfoot**  
**Paper #10**  Sarah B. Nossov, John Gaughan PhD, Nikki Sutliff, Harold J.P. van Bosse

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

11:36 am-11:42 am  **Effectiveness of the Ponseti Method in Treating Foot Deformities in Children with Arthrogryposis**  
**Paper #12**  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)**

1. **Humeral Osteotomy**
   - Crossover Grasp Is Good – M. Claire Manske
   - Crossover Is No Longer Acceptable – Lindley Wall
   - Discussion 5 min

2. **Elbow Flexorplasties**
   - Passive Motion Is Best – Ann VanHeest
   - Active Motion Is Better - Olga Agranovich
   - Discussion 5 min

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)**

1. **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

2. **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)**

1:56 pm-2:02 pm  **Patient Reported Outcomes Measurement Information System (PROMIS) Scores for Children with AMC**  
**Paper #13**  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**  
**Paper #15**  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**  
**Paper #16**  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**  
**Paper #17**  Haluk Altoik, 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**  
**Paper #18**  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 Motorneuron Disease
   Paper #19 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)

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 Klaus Dieterich, Louis Dai, 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 Reggie Hamdy, Caroline Elfassy, Kathleen Montpetit, Delphine Hansen-Jaumard, Noemi Dahan-Oliel,

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
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)
PT: Mobility
1. Early Gait Trainer Use Versus Balance in Braces: Is Walking or Standing Balance the Priority? - Reenee Donohoe
2. Strategies for Progressive Ambulation Using Partial Weight Bearing Support - Suzanne Cherry
3. Mobility for Long Distances: Walking Versus Wheelchair - Chris Church
4. Discussion with Audience

8:41 am-9:10 am Research Abstracts, Registries (30 minutes)

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

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, Noemi Dahan-Oliel

9:02 am-9:10 am Discussion

9:11 am-10:10 am Lower Extremity Abstracts, Foot Deformities (60 minutes)

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

10:51 am-11:20 am Multidisciplinary Clinics Abstracts (30 minutes)

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
   Paper #39 Experience
   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 Kerstin Oestreich, Ruth Lester, Andrea Jester
11:12 am-11:20 am Discussion

11:21 am-11:50 am Lower Extremity Abstracts, Gait (30 minutes)
11:21 am-11:27 am Foot Deformities and Gait Deviations in Children with Arthrogryposis
   Paper #41 Daveda Taylor, Chris F. Church, Nancy Lennon, Michael W. Shrader, Maureen Donohoe, L. Reid Nichols
11:28 am-11:34 am AFO with Dynamic Carbon Fibers Improves Selected Gait Parameters in Children with
   Paper #42 Arthrogryposis
   Monika Wojciechowska, Bart Kowalczyk, Michał Gutswa, Krzysztof Krasowicz
11:35 am-11:41 am Less Invasive Treatment of the Lower Limb and Carbon Fiber Spring Orthoses May Improve
   Paper #43 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)
11:51 am-11:57 am Growth Modulation for Recurrent Flexion Deformity in Arthrogryposis
   Paper #44 Scott N. Oishi, Christopher Stutz, Terri Beckwith, Anna Browning
11:58 am-12:04 am Comparison for Techniques of Treatment of Wrist Flexion Deformity in Arthrogryposis
   Paper #45 Hisham Abdel-Ghani, Mahmoud Mostafa, Hosam Amin
12:05 am –12:11 pm Wrist Contractures in Children with AMC: Long-term Follow Up of Surgical Treatment
   Paper #46 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)
1:51 pm-1:57 pm Guided Growth for Knee Flexion in Arthrogryposis: Neurovascular Encroaching with Bone
   Funnelization
   Paper #47 Geovanny Oleas Santillán, Richard Bowen
1:58 pm-2:04 pm Guided Growth with Hinge Tension Band Plate for Lack Of Extension of the Knee in
   Arthrogryposis
   Paper #48 Miguel A. Galban, Adolfredo Santana
2:05 pm-2:11 pm Correction of Mild to Moderate Arthrogrypotic Knee Flexion Contractures with Guided Growth
   Paper #49 Harold Jacob Pieter 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** David Feldman, Erica Boliek, Troy Rand, Aaron Huser
2:28 pm-2:34 pm  Treatment of Severe Knee Flexion Contractures in Patients With Arthrogryposis  
**Paper #51** Harold Jacob Pieter 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)**
3. Carpal Wedges  
- When and Why I Do Them - Scott Oishi  
- When and Why I don’t - Dan Zlotolow  
  - Discussion 5 min
4. Thumb in Palm  
- When and How to Reconstruct - Dan Zlotolow  
- When to Leave Alone - Andrea Jester  
  - Discussion 5 min

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
1. Patient Reported Outcome, and the Use of the PODCI: Specific Objective Outcomes Looking at Grasp Patterns - Lindley Wall  
2. Health Related Quality of Life and Health Status, Functional Capabilities, and Satisfaction with Orthosis and Gait Analysis - Marie Eriksson  
3. Outcomes, Function, and Quality of Life in Adults with AMC - Haluk Altiok  
4. International Survey of 150+ Adults with AMC, Using Self-report - Bonnie Sawatzky  
5. 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 – Reenee Donohoe
5:11 pm-5:13 pm  Prediction of Ambulation – Reenee 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
5:24 pm-5:26 pm  Maintaining a Delicate Balance – Michelle James
5:27 pm-5:29 pm  Tendon Transfer in the Arthrogrypotic Thumb – Giorgio Pajardi
5:30 pm-5:32 pm  The Thumb in AMC - Dan Zlotolow
5:32 pm-5:34 pm  Does Age Matter - Dan Zlotolow
5:35 pm-5:37 pm  Child Life Services – Jessie Smith
5:38 pm-5:44 pm  Discussion

**5:45 pm 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)
1. 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
2. Knee Flexion Contractures Treatment: Guided Growth Versus Posterior Releases for Mild Contractures? Eva Pontén and Bart Kowalczyk

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

8:56 am-9:02 am Pioneering Wrist Arthroscopy in a Patient with Arthrogryposis
Paper #53 Jeanette Ting, Janak A. Bechar, Laura Sunderland, Tommy Lindau, Andrea Jester, Kirstin Oestreich

9:03 am-9:09 am Effects of the Playskin LiftTM Exoskeletal Garment on Arm Function for Children with Paper 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-Oliel

9:38 am-9:46 am Discussion

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

9:47 am-9:53 am Rehabilitation Needs in Arthrogryposis Multiplex Congenita: Multiple Stakeholder Perspectives
Paper #58 Caroline Elfassy, Noémi Dahan-Oliel, 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 Noemi Dahan-Oliel, 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
Paper #61 Multiplex
Harold J. P. van Bosse, Brandon J. Toll

10:24 am-10:30 am Magnetically Controlled Growing Rods in Scoliosis Secondary to Arthrogryposis Multiplex
Paper #62 Congenita
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)

1) Outcomes Evaluations
2) Standard of Care Guidelines

12:00 pm-12:50 pm – Breakout Sessions (50 minutes)

1) Pre-natal Diagnosis
2) Rehab guidelines - Noémi Dahan-Oliel moderator

1:00 pm-1:50 pm – Breakout Sessions (50 minutes)

1) Classification Systems
2) Discussion session with non-medical participants

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

Summary of breakout sessions