

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 Paper #1	Results and Functional Assessment of Long Head Triceps Transfer in Four Children with Arthrogryposis Bart Kowalczyk, Fąfara Alicja
9:13 am-9:19 am Paper #2	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 Paper #3	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 Paper #4	Functional Improvement After Posterior Elbow Release in Arthrogryptic Children Alicja Fąfara, Kowalczyk Bart
9:43 am-9:49 am Paper #5	Elbow Release and Tricepsplasty in Arthrogryptic Patients- A Long Term Follow Up Study Christopher Stutz, Jue Cao, Anna Browing, Terri Beckwith, Scott N. Oishi
9:50 am-9:56 am Paper #6	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)**

Moderator: Maureen Donohoe

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)**

Moderator:

10:52 am-10:58 am Paper #7	Does Open Reduction of Arthrogyrotic Hips Cause Stiffness? Harold Jacob Pieter van Bosse
10:59 am-11:05 am Paper #8	Reorientational Proximal Femoral Osteotomies for Arthrogyrotic Hip Contractures Harold Jacob Pieter van Bosse, Roger E. Saldana
11:06 am-11:12 am Paper #9	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 Paper #10	Pirani Scores Better Demonstrate Clinical Change in Idiopathic and Non-idiopathic Clubfoot Sarah B. Nossor, 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. Nossor
11:36 am-11:42 am Paper #12	Effectiveness of the Ponseti Method in Treating Foot Deformities in Children with Arthrogyrosis 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

1. Humeral Osteotomy
Crossover Grasp Is Good – Michelle James
Crossover Is No Longer Acceptable – Lindley Wall
Discussion
2. 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: Bart Kowalczyk

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)**

Moderator:

1:56 pm-2:02 pm Paper #13	Patient Reported Outcomes Measurement Information System (PROMIS) Scores for Children with AMC Michelle A. James, Nancy Abarca, M. Claire Manske
2:03 pm-2:09 pm Paper #14	Patient Reported Outcomes in Arthrogyrosis Lindley Wall, Charles A Goldfarb, Summer Roberts, Donald S. Bae, Carley Vuillermin, CoULD Registry
2:10 pm-2:16 pm Paper #15	Participation Among Children and Youth with Arthrogyrosis 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 Paper #16	Using the Oswestry Disability Index for Pain and Disability in Arthrogyrosis Multiplex Congenita Bonita J Sawatzky, Rebecca Miller, Talon Jones, John Street
2:33 pm-2:39 pm Paper #17	Long-term Follow Up on Quality of Life and Function of Adults with Arthrogyrosis Haluk Altiok, Ann Flanagan, Joseph J. Krzak, Sahar Hassani
2:40 pm-2:46 pm Paper #18	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 Paper #19	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 Paper #20	Arthrogyrosis - Genetic Update Judith G. Hall, Jeff Kiefer
3:29 pm-3:35 pm Paper #21	Natural Progression of Orthopedic Deformities in Bruck Syndrome 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:

3:45 pm-3:51 pm Paper #22	Defining AMC: Towards a Consensus on Terminology Sarah Cachecho, Caroline Elfassy, Peter Rosenbaum, Reggie Hamdy, Noémi Dahan-Oliel
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3:52 pm-3:58 pm Paper #23	An Initial Report on a Grading System for Global Assessment of the Child with Amyoplasia Bart Kowalczyk, Anna Kuźnik-Buziewicz, Alicja Fąfara, Bogusława Banaś
3:59 pm-4:05 pm Paper #24	Relationship of Ambulatory Function Based on Infantile Lower Extremity Posture Types in Amyoplasia Maureen Donohoe, Blazej Pruszcynski, Kenneth Rogers, James Richard Bowen
4:06 pm-4:12 pm Paper #25	Disability in Adults with Arthrogyrosis Is Severe, Partly Invisible, and Varies by Genotype Klaus Dieterich, Louis Dai, Marie Jaeger, Pierre-Simon Jouk, Dominique Perennou
4:13 pm-4:21 pm	Discussion
4:22 pm-4:28 pm Paper #26	Functional Outcomes Among Children with AMC: Retrospective Review on 114 Charts Reggie Hamdy, Caroline Elfassy, Kathleen Montpetit, Delphine Hansen-Jaumard, Noemi Dahan-Oliel,
4:29 pm-4:35 pm Paper #27	Health-related Quality of Life and Orthosis Use in a Swedish Population with Arthrogyrosis Marie Eriksson, Li Villard, Anna-Karin Kroksmark, Åsa Bartonek
4:36 pm-4:44 pm Paper #28	Preliminary Report on a Method of Assessing Functional Hip Motion 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 Arthrogyrosis 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)

Moderator: Lisa Wagner

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)

Moderator:

8:41 am-8:47 am Paper #29	Outcomes of Adults with Arthrogryposis Multiplex Congenita Hirmand Nouraei, Bonita Sawatzky
8:48 am-8:54 am Paper #30	Arthrogryposis Multiplex Congenita: A Multi-site Pilot Registry in Pediatrics Noémi Dahan-Oliel, Tanya Bedard, Vasiliki Darsaklis, Judith G. Hall, Harold J.P. van Bosse, Reggie Hamdy
8:55 am-9:01 am Paper #31	The Creation of an Adult Arthrogryposis Research Registry 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)

Moderator:

9:11 am-9:17 am Paper #32	Conception of Achilles Tenotomy in Children with Arthrogryposis Svetlana Trofimova, Olga Agranovich, Denis Derevyanko
9:18 am-9:24 am Paper #33	Treatment of Arthrogrypotic Clubfeet Using Ponseti Casts and Posterior Ankle Release Bart Kowalczyk, Anna Kuźnik
9:25 am-9:31 am Paper #34	Longitudinal Management of Recurrent Arthrogrypotic Clubfeet with Ponseti Management 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 Paper #35	Identifying Equinovarus Variant of Arthrogrypotic Clubfoot Sarah B. Nossov, Nikki Sutliff, Harold J.P. van Bosse
9:48 am-9:54 am Paper #36	Treatment Severe Deformities of Plano-valgus Feet in Children with Arthrogryposis Ekaterina Petrova, Svetlana Trofimova, Dmitrii Buclaev, Evgenia Kochenova
9:55 am-10:01 am Paper #37	Reducing Recurrence of Equinus in Tibial Dorsiflexion Osteotomies by Tendon Transfer and Wolff's Law Hari Prem

10:02 am-10:10 am	Discussion
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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)**

Moderator: Maureen Donohoe

10:51 am-10:57 am Paper #38	An AMC Multidisciplinary Clinic: Using the COPM to Ensure a Family-centered Model of Care Emily Lecker, Reggie Hamdy, Chantal Janelle, Kelly Thorstad, Noémi Dahan-Oliel
10:58 am-11:04 am Paper #39	AMC Patient Management at the University Hospital Grenoble/ France: a Single Center Experience Klaus Dieterich, Gipsy Billy, Véronique Bourg BOURG, Dominique Perennou, Pierre-Simon Jouk
11:05 am-11:11 am Paper #40	The Development of an MDT Approach to Arthrogyrosis at Birmingham Children's Hospital 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)**

Moderator:

11:21 am-11:27 am Paper #41	Foot Deformities and Gait Deviations in Children with Arthrogyrosis 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 Arthrogyrosis Monika Wojciechowska, 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

11:51 am-11:57 am Paper #44	Growth Modulation for Recurrent Flexion Deformity in Arthrogyrosis Scott N. Oishi, Christopher Stutz, Terri Beckwith, Anna Browning
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11:58 am-12:04 am 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

Gene Ontology (GO) Analysis and Pathways: Potential for therapies— Judith Hall

1:51 pm-2:50 pm Lower Extremity Abstracts, Knee (60 minutes)

Moderator:

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

2:51 pm-3:40 pm Upper Extremity Didactic Session (50 minutes)

Moderator: Michelle James

3. Carpal Wedges

When and Why I Do Them - Scott Oishi

When and Why I don't – Max Horowitz

Discussion

4. 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 Arthrogyriposis: 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 Altioek
4. Pros and Cons of Using Various Self-Report and Clinician-Administered Outcome Measures for Adults with AMC - Bonnie Sawatzky
5. Panel Discussion

5:01 pm-5:44 pm Arthrogyriposis Acumen (45 minutes)

Moderator: Harold van Bosse

5:01 pm-5:03pm	Introduction
5:03 pm-5:05pm Acumen #1	External Tibial Torsion Accompanying Arthrogyriptic Clubfoot Deformities Harold van Bosse
5:05 pm-5:07 pm Acumen #2	The Power of the Wedge Harold van Bosse
5:08 pm-5:10 pm Acumen #3	Standing Balance: the Art of the Shoe Wedge Reenee Donohoe
5:11 pm-5:13 pm Acumen #4	Prediction of Ambulation Reenee Donohoe
5:14 pm-5:16 pm Acumen #5	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 Acumen #6	Maintaining a Delicate Balance Michelle James
5:27 pm-5:29 pm Acumen #7	Tendon Transfer in the Arthrogyriptic Thumb Giorgio Pajardi
5:30 pm-5:32 pm Acumen #8	The Thumb in AMC Dan Zlotolow
5:32 pm-5:34 pm Acumen #9	Does Age Matter Dan Zlotolow
5:35 pm-5:37 pm Acumen #10	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)

Moderator:

1. Is Talectomy Still a Valuable Option for Arthrogyrotic 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
3. Severe Knee Flexion Contractures: Soft Tissue Releases with Frames or Osteotomies? - 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 Paper #53	Pioneering Wrist Arthroscopy in a Patient with Arthrogyrosis Jeanette Ting, Janak A. Bechar, Laura Sunderland, Tommy Lindau, Andrea Jester, Kirstin Oestreich
9:03 am-9:09 am Paper #54	Effects of the Playskin Lift™ Exoskeletal Garment on Arm Function for Children with Arthrogyrosis Iryna Babik, Andrea B. Cunha, Michele A. Lobo
9:10 am-9:16 am	Discussion
9:17 am-9:23 am Paper #55	Sensory Modulation and Emotional Regulation in Posterior Capsular Elbow Release Patients Heather Rose Ford, Jacqueline Macri
9:24 am-9:30 am Paper #56	Patient and Parent Satisfaction after Upper Limb Surgery Andrea Anna Maria Jester, Kerstin Oestreich, Laura Sunderland, Ruth Lester
9:31 am-9:37 am Paper #57	An Upper Extremity Evaluation Tool for Children with Arthrogyrosis Multiplex Congenita 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 Abstracts and Spine Abstracts (48 minutes)

Moderator: Suzanne Cherry

9:47 am-9:53 am Paper #58	Rehabilitation Needs in Arthrogyrosis Multiplex Congenita: Multiple Stakeholder Perspectives Caroline Elfassy, Noémi Dahan-Oliel, Vasiliki Darsaklis, Laurie Snider, Cynthia Gagnon, Reggie Hamdy
9:54 am-10:00 am Paper #59	Towards the Development of Best Practice Guidelines for Rehabilitation Noemi Dahan-Oliel, Kathleen Montpetit, Cristina Patulli, Lisa Wagner, Maureen Donohoe, Reggie Hamdy

10:01 am-10:07 am Paper #60	Measuring Efficacy of Physical Rehabilitation in Children and Adults with Arthrogryposis Maureen Donohoe
10:08 am-10:16 am	Discussion
10:17 am-10:23 am Paper #61	Serial Derotational Spinal Casting in Early Onset Scoliosis Secondary to Arthrogryposis Multiplex Harold J. P. van Bosse, Brandon J. Toll
10:24 am-10:30 am Paper #62	Magnetically Controlled Growing Rods in Scoliosis Secondary to Arthrogryposis Multiplex 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 – Reenee Donohoe, facilitator
- 2) Standard of Care Guidelines

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

- 1) Pre-natal Diagnosis and intervention – Judith Hall and Philip Giampietro, facilitators
- 2) Rehab guidelines - Noémi Dahan-Oliel, facilitator

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

- 1) Classification Systems – Judith Hall, facilitator
- 2) 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