### The Howard H. Steel Conference on Pediatric Spinal Cord Injury and Dysfunction

**Course Chairs:** Randal R. Betz, MD, MJ Mulcahey PhD, OTR/L, Lawrence C. Vogel, MD, Kathy Zebracki, PhD

#### Wednesday, September 12, 2018

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<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker/Location</th>
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<tr>
<td>6:30 AM - 8:00 AM</td>
<td>Breakfast</td>
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<tr>
<td>8:00 AM - 8:10 AM</td>
<td>Welcome and Introduction</td>
<td>MJ Mulcahey, PhD, OTR/L USA</td>
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<tr>
<td>8:10 AM - 8:40 AM</td>
<td>Keynote: <em>Activity-based Therapy Targeting Neuromuscular Recovery after Pediatric Spinal Cord Injury</em></td>
<td>Andrea Behrman, PhD USA</td>
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<td>8:40 AM - 8:50 AM</td>
<td>Discussion</td>
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<tr>
<td>8:50 AM - 10:11 AM</td>
<td>Session I: Free Papers – International Data Sets and Measurement</td>
<td>Moderator: Daniel Graves, PhD USA</td>
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<tr>
<td>8:50 AM - 9:00 AM</td>
<td>International Data Sets and NINDS CDE: Overview and Application in Pediatric SCI</td>
<td>Vanessa Noonan, PhD CANADA</td>
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<td>9:00 AM - 9:20 AM</td>
<td>Psychometric Examination of the International SCI Basic Caregiver Data Set and the International SCI Basic Bowel Data Set in Pediatric SCI</td>
<td>Lawrence C. Vogel, MD USA</td>
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<td>9:20 AM - 9:28 AM</td>
<td>Illustration and Application of the International SCI Basic Education Data Set</td>
<td>Marika Augutis, PhD SWEDEN</td>
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<td>9:28 AM - 9:38 AM</td>
<td>Discussion</td>
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<td>9:38 AM - 9:46 AM</td>
<td>Development of a SCI Module for the Pediatric Quality of Life Inventory (PedsQL™)</td>
<td>Kathy Zebracki, PhD USA</td>
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<td>9:46 AM - 10:01 AM</td>
<td>Measures of Physical Function, Activity and Participation for Children and Youth with SCI</td>
<td>MJ Mulcahey, PhD, OTR/L USA</td>
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<td>10:01 AM - 10:11 AM</td>
<td>Discussion</td>
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<td>10:11 AM - 10:41 AM</td>
<td>Break to Visit Exhibits &amp; View Posters</td>
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<td>10:41 AM - 11:01 AM</td>
<td>The Steven M. Haley Memorial Lectureship: <em>Abdominal Functional Electrical Stimulation to Reduce Respiratory Complications in Spinal Cord Injury</em></td>
<td>Bonne Lee MBBS, PhD AUSTRALIA</td>
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<td>11:01 AM - 11:11 AM</td>
<td>Discussion</td>
<td>Moderator: Isabel Chapman, BAppSci(Physio) AUSTRALIA</td>
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<td>11:11 AM - 11:45 AM</td>
<td>Session II: Free Papers - Outcomes</td>
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<td>11:11 AM - 11:19 AM</td>
<td>Traumatic Spinal Cord Injuries: A Retrospective Cohort Study of Children Seen in Western Australia Between 1996 and 2016</td>
<td>Rachel Dwyer, MBBS AUSTRALIA</td>
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<td>11:19 AM - 11:27 AM</td>
<td>Teens &amp; Trauma: A Ten-Year Review of Etiologies of Adolescent ABIs and SCIs</td>
<td>Cathi Dugger, BS, PT USA</td>
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<td>11:27 AM - 11:35 AM</td>
<td>Teamwork, Innovation and Inclusion: A Case Study</td>
<td>Toni Blanch, BAAppSc (OT) AUSTRALIA</td>
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<td>11:35 AM - 11:45 AM</td>
<td>Discussion</td>
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Course Chairs: Randal R. Betz, MD, MJ Mulcahey PhD, OTR/L, Lawrence C. Vogel, MD, Kathy Zebracki, PhD

11:45 AM - 12:45 PM  Session III: Neuromuscular Scoliosis Panel
Isabel Chapman, Physiotherapist AUSTRALIA
Andrew Cree, MD AUSTRALIA
John Ferguson, MD NEW ZEALAND
Michael Johnson, MD AUSTRALIA
MJ Mulcahey, PhD, OTR/L USA

Moderator: Randal R. Betz, MD USA

12:45 PM - 2:00 PM  Lunch Symposium: Overcoming Implicit Bias and Other Barriers to Better Adherence to Bladder Management Following Spinal Cord Injury
Andrei Krassioukov MD, PhD, FRCPC CANADA

Introduction: Lawrence C. Vogel, MD USA

1:45 PM - 2:00 PM  Lunch Panel Discussion
Antoinette Botman, MD AUSTRALIA
Allison Graham, MBChB UNITED KINGDOM
Jens Wöllner, MD SWITZERLAND
Kathy Zebracki, PhD USA

2:00 PM - 3:01 PM  Session IV: Spina Bifida Symposium
Kathy Zebracki, PhD USA

2:00 PM - 2:10 PM  Perspective on Spinal Bifida
Inge Eriks-Hoogland, MD, PhD SWITZERLAND

2:10 PM - 2:18 PM  Parental Perspectives Regarding Prenatal Surgery for Myelomeningocele
Amy Joy Houtrow, MD, PhD, MPH USA

2:18 PM - 2:28 PM  Neurodevelopmental Outcomes at 30 Months of Age for Children Enrolled in the Moms Trial by Presence of Hydrocephalus and Shunt Status
Amy Joy Houtrow, MD, PhD, MPH USA

2:28 PM - 2:38 PM  Discussion

2:38 PM - 2:46 PM  Principles of Neuro-Urological Treatment Across the Life Span in Persons with Spina Bifida
Jens Wöllner, MD SWITZERLAND

2:46 PM - 2:56 PM  The Spina Bifida Association Guidelines for Quality of Life and Sexual Health and Education
Kathleen Sawin, PhD, CPNP-PC USA

2:56 PM - 3:01 PM  Discussion

3:01 PM - 3:21 PM  Keynote: Helping Children Breath: The Important Role of Diaphragm Pacing
Raymond Onders, MD USA

Introduction: Andrei Krassioukov MD, PhD, FRCPC, CANADA

3:21 PM - 3:31 PM  Discussion

3:31 PM - 4:00 PM  Break to Visit Exhibits & View Posters

4:00 PM - 4:26 PM  Session V: Free Papers - Needs and Priorities of Families
Moderator: Antoinette Botman, MD AUSTRALIA

4:00 PM - 4:08 PM  Health and Life Priorities for Children and Young Persons With Spinal Cord Injuries and Their Parents and Caregivers
Allison Graham, MBChB UNITED KINGDOM

Tamara Powell, PHD USA

4:16 PM - 4:26 PM  Discussion

4:26 PM - 4:46 PM  The Newton C. McCollough Lecture: Pediatric Non-Traumatic Spinal Cord Lesions
Peter New MD, AUSTRALIA

Introduction: Kathy Zebracki, PhD USA

4:46 PM - 5:00 PM  Closing Remarks
MJ Mulcahey, PhD, OTR/L USA
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Posters
1. 10 Year Experience Of Intra-Detrusor Botulinum Toxin Type A Injections In Children And Young People With Neurogenic Detrusor Over-Activity Following Spinal Cord Injury – Is It A Long Term Management Solution? Author: Sarah Knight
2. Long Term Physical, Psychosocial, Participation Outcomes And Burden Of Disability In Childhood Onset Transverse Myelitis. Author: Jodie Thompson
3. Appraisals Of Disability In Middle Adulthood Following Pediatric-Onset Spinal Cord Injury. Author: Kathy Chlan
4. Barriers in Accessing Adult Healthcare for Transitioning Youth with Spinal Cord Injury. Author: Kathy Zebracki
5. Spinal Cord Injury In The Pediatric Population - An International Multicenter Study In Norway, Sweden, China, USA, Russia, Israel And Palestine. Author: Kirsti Skavberg Roaldsen