September 12, 2018

Dear Colleagues,

On behalf of the Steel Assembly, we are pleased to welcome you to The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction in Sydney, Australia.

This one-day, 2018 ISCoS Pre-Course will utilize a combination of didactics, free papers, point-counter-point debate, scientific posters and audience engagement to present, review and discuss evidence based pediatric SCI/D best practice, including the development and use of pediatric SCI basic data sets, contemporary controversies on complex problems relevant to pediatric SCI/D, and outcomes of pediatric SCI/D on the child and caregivers.

**Featured Lectures**

- **Dr. Bonne Lee** - The Stephen M. Haley Memorial Lecture
  *Epidemiology of Pediatric SCI/D World-Wide*
- **Dr. Peter New** - The Newton C. McCollough Lecture
  *Pediatric Non-Traumatic Spinal Cord Lesions*
- **Andrea Behrman, PhD** - Keynote
  *Activity-Based Therapy Targeting Neuromuscular Recovery After Pediatric Spinal Cord Injury*

We hope you take the time to enjoy the lively city of Sydney, with its natural beauty and variety of activities. *The Howard H. Steel Course on Pediatric SCI/D* will be successful as we welcome attendees from around the world, hungry for knowledge about pediatric SCI/D.

Thank you for joining us!

*MJ Mulcahey, PhD, OTR/L*
Thomas Jefferson University
Philadelphia, PA

*Kathy Zebracki, PhD*
Shriners Hospitals for Children
Chicago, IL

*Randal Betz, MD*
Institute for Spine and Scoliosis
Lawrenceville, NJ

*Lawrence Vogel, MD*
Shriners Hospitals for Children
Chicago, IL

**Complimentary WiFi**

Complimentary WiFi is available to all meeting attendees through the ICC Sydney.

Network: **ICC Sydney**
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Course Chairs

Randal Betz, MD
Institute for Spine and Scoliosis
Lawrenceville, NJ

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Philadelphia, PA

Lawrence Vogel, MD
Shriners Hospitals for Children
Chicago, IL

Kathy Zebracki, PhD
Shriners Hospitals for Children
Chicago, IL

Course Faculty

Marika Augutis, PhD
SWEDEN

Therese Johnston, PhD
UNITED STATES

Peter New, MD
AUSTRALIA

Andrea Behrman, PhD
UNITED STATES

Andrei Krassioukov, MD, PhD, FRCPC
CANADA

Vanessa Noonan, PhD
CANADA

Antoinette Botman, MD
AUSTRALIA

Bonne Lee, MBBS, PhD
AUSTRALIA

Jens Wöllner, MD
SWITZERLAND

Daniel Graves, PhD
UNITED STATES

Daniel Graves, PhD
UNITED STATES

Paper & Poster Presenters

Maria J. Andrade, PhD
PORTUGAL

Rachel Dwyer, MBBS
AUSTRALIA

Raymond Onders, MD
UNITED STATES

Toni Blanch, BAppSc (OT)
AUSTRALIA

Inge Eriks-Hoogland, MD, PhD
SWITZERLAND

Aaron Powell, PhD
UNITED STATES

Isabel Chapman, BAppSci(Physio)
AUSTRALIA

John Ferguson, MD
NEW ZEALAND

Kirsti Skavberg Roaldsen, PhD
NORWAY

Andrew Cree, MD
AUSTRALIA

Amy Joy Houtrow, MD, PhD, MPH
UNITED STATES

Kathleen Sawin, PhD, CPNP-PC
UNITED STATES

Kyle C. Deane, PhD
UNITED STATES

Alicia M. January, PhD
UNITED STATES

Anke Scheel-Sailer, MD
SWITZERLAND

Cathi Dugger, BS, PT
UNITED STATES

Michael Johnson, MD
AUSTRALIA

Jodie Thompson BN
AUSTRALIA

Sarah Knight, MA, MSc, PhD
UNITED KINGDOM
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

6:30 AM - 8:00 AM  Breakfast

8:00 AM - 8:10 AM  Welcome and Introduction  MJ Mulcahey, PhD, OTR/L USA

8:10 AM - 8:40 AM  Keynote: Activity-based Therapy Targeting Neuromuscular Recovery after Pediatric Spinal Cord Injury  Andrea Behrman, PhD USA

8:40 AM - 8:50 AM  Discussion

8:50 AM - 10:11 AM  Session I: Free Papers – International Data Sets and Measurement  Moderator: Daniel Graves, PhD USA

8:50 AM - 9:00 AM  International Data Sets and NiNDS CDE: Overview and Application in Pediatric SCI  Vanessa Noonan, PhD CANADA

9:00 AM - 9:20 AM  Psychometric Examination of the International SCI Basic Caregiver Data Set and the International SCI Basic Bowel Data Set in Pediatric SCI  Lawrence C. Vogel, MD USA

9:20 AM - 9:28 AM  Illustration and Application of the International SCI Basic Education Data Set  Marika Augutis, PhD SWEDEN

9:28 AM - 9:38 AM  Discussion

9:38 AM - 9:46 AM  Development of a SCI Module for the Pediatric Quality of Life Inventory (PedsQL™)  Kathy Zebracki, PhD USA

9:46 AM - 10:01 AM  Measures of Physical Function, Activity and Participation for Children and Youth with SCI  MJ Mulcahey, PhD, OTR/L USA

10:01 AM - 10:11 AM  Discussion

10:11 AM - 10:41 AM  Break to Visit Exhibits & View Posters


11:01 AM - 11:11 AM  Discussion

11:11 AM - 11:45 AM  Session II: Free Papers - Outcomes  Moderator: Isabel Chapman, BAppSci(Physio) AUSTRALIA

11:11 AM - 11:19 AM  Traumatic Spinal Cord Injuries: A Retrospective Cohort Study of Children Seen in Western Australia Between 1996 and 2016  Rachel Dwyer, MBBS AUSTRALIA

11:19 AM - 11:27 AM  Teens & Trauma: A Ten-Year Review of Etiologies of Adolescent ABIs and SCIs  Cathi Dugger, BS, PT USA

11:27 AM - 11:35 AM  Teamwork, Innovation and Inclusion: A Case Study  Toni Blanch, BAppSc (OT) AUSTRALIA

11:35 AM - 11:45 AM  Discussion
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
Jens Wöllner, MD SWITZERLAND
Kathy Zebracki, PhD USA

2:00 PM - 3:01 PM  **Session IV: Spina Bifida Symposium**

2:00 PM - 2:10 PM  Perspective on Spinal Bifida
Inge Erks-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  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**

4:00 PM - 4:08 PM  Health and Life Priorities for Children and Young Persons With Spinal Cord Injuries and Their Parents and Caregivers
Anke Scheel-Sailer, MD SWITZERLAND

Aaron Powell, MD 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 - 4:56 PM  Discussion

4:46 PM - 5:00 PM  **Closing Remarks**
MJ Mulcahey, PhD, OTR/L USA
Poster Directory

*Presenting Author

**Longitudinal Outcomes**

**Poster Abstract # 2348**
10 Year Experience Of Intrac-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?
Sarah Louise Knight, MA, MSc, PhD; Natasha Wallace, RN*; Angela Gall, MB, BS; Frank Lee, MD; Rizwan Hamid, MD

**Poster Abstract # 2355**
Long Term Physical, Psychosocial, Participation Outcomes And Burden Of Disability In Childhood Onset Transverse Myelitis
Jodie Thompson, BN*; Kathryn Benerjee, MBCHB, MRCSPCH, MSc, FAFRM; Karen Burton, Bach of Psy, Mast of Clinical Neuropsychology; Anne Marie Sarandrea, Bachelor and Masters Degree in Clinical Psychology

**Poster Abstract # 2370**
Quality Of Sleep And Psychosocial Functioning In Pediatric-Onset Spinal Cord Injury
Alicia M. January, PhD*; Kathy Zebracki, PhD; Kathy Chlan, BA; Lawrence C. Vogel, MD

**Measurement and Outcomes**

**Poster Abstract # 2346**
Appraisals Of Disability In Middle Adulthood Following Pediatric-Onset Spinal Cord Injury
Kathy Zebracki, PhD*; Kathy Chlan, BA; Paul Kennedy, D.Phil, MSc, FBPsS, C.Psychol; Lawrence C. Vogel, MD

**Psychosocial and Environmental**

**Poster Abstract # 2340**
Barriers in Accessing Adult Healthcare for Transitioning Youth with Spinal Cord Injury
Kathy Zebracki, PhD*; Alexander Porto, BA; Lara Anderson, Student; Lawrence C. Vogel, MD

**Poster Abstract # 2381**
Self-Report Of Happiness In Adults With Pediatric-Onset Spinal Cord Injury
Kyle C. Deane, PhD*; Kathy Chlan, BA; Lawrence C. Vogel, MD; Kathy Zebracki, PhD

**Rehabilitation and Rehabilitation Research**

**Poster Abstract # 2363**
Spinal Cord Injury In The Pediatric Population - An International Multicenter Study In Norway, Sweden, China, USA, Russia, Israel And Palestine
Kirsti Skavberg Roaldsen, PhD*; Vivien Jørgensen, PhD; Susanne Sällström, MSc; Peter New, MBBS, Mst Clin Epi, PhD, FAFRM (RACP); Johan Stanghelle, Prof.; Marika Augusti, PT/PhD

**Poster Abstract # 2378**
Organizing A Pediatric Sci Follow-Up In Sweden
Marika Augusti, PT/PhD*; Eva Sandvall, MD; Per Ertzgaard, MD

**Spine**

**Poster Abstract # 2377**
Is Autonomic Dysreflexia A Cause Of Respiratory Dysfunction After Sci?
Kirsti Skavberg Roaldsen, PhD*; Vivien Jørgensen, PhD; Susanne Sällström, MSc; Maria J. Andrade, PhD*; Filipe Quintas, MD; André Silva, MD; Patricia Cruz, MD
Our Mission

Promoting **best practice** and **evidence-informed standards of care** in pediatric Spinal Cord Injury and Dysfunction (SCI/D) **across the globe**.

Visit steelassembly.org today!

Steel Assembly is an affiliate of The American Spinal Injury Association (ASIA).

Steel Assembly is an organization of health care, rehabilitation and social service professionals with expertise in pediatric SCI/D, who provide education and training to professionals on pediatric spinal cord injury dysfunction (SCI/D), and who establish evidence-informed standards for pediatric SCI research and care.

All 2018 Howard H. Steel Course on Pediatric SCI/D Attendees

MEMBERSHIP - **FREE**!

Apply online at steelassembly.org before **September 30, 2018**

**Membership Benefits**
- Networking with professionals and those affected by pediatric SCI/D
- Access to Steel Link – the online education portal (coming soon!)
- Access to archived conference proceedings

**Who Should be a Member?**
Professionals and those affected by pediatric spinal cord injury and dysfunction Such as, but not limited to:
- Medical Professionals
- Family Members and/or Individuals
- Educators