# Third World Congress on Spina Bifida Research and Care

## Agenda

### Thursday, March 16, 2017

<table>
<thead>
<tr>
<th>Event</th>
<th>Time</th>
<th>Location</th>
</tr>
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<tbody>
<tr>
<td>Opening Reception with Exhibitors and Poster Viewing</td>
<td>6:00 pm – 8:00 pm</td>
<td>Pavilion</td>
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### Friday, March 17, 2017

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<thead>
<tr>
<th>Event</th>
<th>Time</th>
<th>Location</th>
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<tbody>
<tr>
<td>Breakfast</td>
<td>7:00 am – 8:00 am</td>
<td>Commodore Foyer</td>
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<tr>
<td>Opening Remarks</td>
<td>8:00 am - 8:30 am</td>
<td>Commodore C,D,E</td>
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- **Speakers:** Carlos Estrada, MD and Dario Fauza, MD

Dr. Estrada and Dr. Fauza are noted experts in stem cell research with areas of interest important in Spina Bifida. In addition to their own work they will inform about the current state of stem cell research in general and applicability to Spina Bifida, as this is being asked by families to clinicians.

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<th>Event</th>
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<tr>
<td>Regenerative Medicine and Spina Bifida</td>
<td>8:30 am – 9:30 am</td>
<td>Commodore C,D,E</td>
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- **Speakers:** Judy Thibadeau, RN, BSN, MN Health Scientist National Center on Birth Defects & Developmental Disabilities, Division of Human Development & Disability, Centers for Disease Control and Prevention

This session will focus on current activities at the CDC related to Spina Bifida, with a particular focus on data coming out of the National Spina Bifida Patient Registry.

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<th>Event</th>
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<th>Location</th>
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<td>Update and Progress on the CDC National Spina Bifida Patient Registry</td>
<td>9:30 am – 10:30 am</td>
<td>Commodore C,D,E</td>
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<td>Morning Break</td>
<td>10:30 am – 10:45 am</td>
<td>Commodore Foyer</td>
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<th>Event</th>
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<tr>
<td>SBA’s Role in Collaborative Care</td>
<td>10:45 am – 11:15 am</td>
<td>Commodore C,D,E</td>
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Speaker: Sara Struwe, MPA, President and CEO, SBA

Sara Struwe will present on the activities occurring at the Spina Bifida Association and focus on the current status and plans regarding the ongoing development of the Spina Bifida Collaborative Care Network.

Improving Care in Spina Bifida: Health Care Guidelines Update
11:15 am - 12:00 pm
Location: Commodore C,D&E

Speaker: Brad Dicianno, MD

As a member of the Health Care Guidelines Steering Committee and a co-chair of the Health Care Guidelines efforts in supervision of the different working groups, Dr. Dicianno will present an overview of the Health Care Guidelines process, some information from the working groups, and next steps to finalize the new Health Care Guidelines.

Boxed Lunch, Poster Viewing, Exhibitors 12:00 pm – 1:00 pm
Location: Pavilion

Neurosurgery Breakout
1:00 pm – 3:00 pm
Location: Commodore B

Outcomes of Prenatal Surgery (PRENS) Versus (v.) Postnatal Surgery (POSTNS) for Closure of Myelomeningocele (MM)
Studying Patients (pts) in the National Spina Bifida Patient Registry (NSBPR)
Gordon Worley, MD
1:00 pm - 1:15 pm

Chiari II Decompression in Myelomeningocele Patients in the National Spina Bifida Patient Registry
Irene Kim, MD
1:15 pm - 1:30 pm

Rate of Shunt Revision as a Function of Age in a Population of Myelomeningocele Patients with Shunted Hydrocephalus
Anastasia Arynchyna, MPH, CCRP
1:30 pm - 1:45 pm

Sleep Disordered Breathing in Myelomeningocele Patients
Brandon Rocque, MD, MS
1:45 pm - 2:00 pm

Jeffrey Blount, MD
2:00 pm - 2:15 pm

Practice Preferences for Neurosurgical Management in Spina Bifida: A Survey of the American Society for Pediatric Neurosurgery- Part II: Issues of Childhood through Transition
Jeffrey Blount, MD
2:15 pm - 2:30 pm
Practice Preferences for Neurosurgical Management in Spina Bifida: A survey of the American Society for Pediatric Neurosurgery- Part III: Neurosurgical Perspective on Transitional Care
Jeffrey Blount, MD
2:30 pm - 2:45 pm

Hydrocephalus in Patients with Myelomeningocele in the National Spina Bifida Patient Registry
Irene Kim, MD
2:45 pm - 3:00 pm

Urology Breakout
1:00 pm – 3:00 pm
Location: Commodore E

Baseline Urinary Tract Imaging Infants with Spina Bifida
Michelle Baum, MD
1:00 pm - 1:06 pm

Examining the Role of Screening Renal Ultrasound in Spina Bifida During the First Year of Life
Gene Huang, PhD
1:06 pm - 1:12 pm

Cause-specific Mortality in Patients with Spina Bifida (SB) and End Stage Renal Disease (ESRD)
Lijing Ouyang, BA, MA, PhD
1:12 pm - 1:18 pm

Ultrasound Estimated Bladder Weight Correlates with Videourodynamic Studies in Neurogenic Bladder Dysfunction
Stephen Zderic, MD
1:18 pm - 1:24 pm

DMSA in Young Children with Myelodysplasia: Should this be Routinely Obtained?
Matthew Timberlake, MD
1:24 pm - 1:30 pm

Highly Elevated Cystatin C GFR in Pediatric Myelomeningocele Patients: Does it Indicate Nephropathy?
Brian VanderBrink, BS, MD
1:30 pm - 1:33 pm

Considerations of Urinary Bacterial Colonization in Patients with Myelomeningocele at Time of Urologic Testing
Janae Preece, MD
1:33 pm - 1:36 pm

Discussion
1:36 pm – 1:52 pm

Agreement Between Electronic Medical Records and Self-Reported Urologic Domains in the National Spina Bifida Patient Registry
Christopher Halline, BA
1:52 pm - 1:56 pm

Lipomyelomeningocele for the Urologist: Should We View it the Same as Myelomeningocele?
Elizabeth Yerkes, MD
1:58 pm - 2:04 pm
Early Postnatal Bladder Function in Fetoscopic Myelomeningocele Repair Patients
Gene Huang, PhD
2:04 pm - 2:10 pm

Urology Protocols in Patients that have Undergone in Utero Repair of Myelomeningocele: Room for Improvement
Brian VanderBrink, BS, MD
2:10 pm - 2:16 pm

Deferment in Urinary Self-Catheterization Among Individuals Living with Spina Bifida: A Call to Action
Heidi Castillo, MD
2:16 pm - 2:22 pm

Conservative Use of CIC in Newborns with Myelodysplasia: Report of Clinical Outcomes
Matthew Timberlake, MD
2:22 pm - 2:28 pm

Pediatric IC: Education for Community Based Collaboration
Suzanne Fortuna, MSN, RN, APRN-BC, CNS, FNP
2:28 pm - 2:31 pm

History of Urologic Management of Spina Bifida Pre and Post Introduction of Clean Intermittent Catheterization
Rajeev Chaudhry, MD
2:31 pm - 2:34 pm

Discussion
2:34 pm – 3:00 pm

Orthopedics Breakout
1:00 pm – 3:00 pm
Location: Britannia/Cambria

Mid-term Results of Ponseti Method for Clubfoot in Patients with Myelomeningocele (MM)
Vineeta Swaroop, MD
1:00 pm - 1:06 pm

Foot Pressure Sores in Patients with Spina Bifida
Michael Conklin, BS, MD
1:06 pm - 1:12 pm

Assessing Plantar Pressure Characteristics in Children with Spina Bifida by Neurological Level of Impairment
Aaron Powell, MD
1:12 pm - 1:18 pm

Discussion
1:18 pm – 1:24 pm

Hip Status and Long-Term Functional Outcomes in MM
Vineeta Swaroop, MD
1:24 pm - 1:30 pm

Comparing Outcomes of Tibial Derotational Osteotomy (TDO) in Cerebral Palsy (CP) vs Myelodysplasia (MM)
Vineeta Swaroop, MD
1:30 pm - 1:36 pm

Diversities of Neck-Shaft Angle of Proximal Femur in Patients with Spina Bifida
Stanislav Ivanov, MD
1:36 pm - 1:42 pm

Discussion
1:42 pm – 1:48 pm

Gait Analysis Data Alters Surgical Decision Making in Youth with Spina Bifida
Jeffrey Thomson, MD
1:48 pm - 1:54 pm

Use of Plantar Pressures and Observational Video in the Diagnosis of Tethered Cord in Spina Bifida: An Update
Aaron Powell, MD
1:54 pm - 2:00 pm

Three-Dimensional Gait Data Influences Pathology Identification in Youth with Spina Bifida
Deirdre Ryan, MD
2:00 pm - 2:06 pm

Prophylactic Detethering Does Not Prevent Perioperative Neurologic Loss in Myelomeningocele Scoliosis Surgery
Lawrence Karlin, MD
2:12 pm - 2:18 pm

Distraction Based Growth Friendly Surgery for the Treatment of Hyperkyphosis in Children with Myelomeningocele: Rib Based Systems Are Safer than Spine Based Systems
Lawrence Karlin, MD
2:18 pm - 2:24 pm

Sub-Laminar Polyester Band Fixation Construct in the Treatment of Neuromuscular Scoliosis
Samuel Rosenfeld, MD
2:24 pm - 2:30 pm

Discussion
2:30 pm – 2:36 pm

Factors Associated with Mobility Outcomes in a National Spina Bifida Patient Registry
Brad Dicianno, MD
2:36 pm – 2:40 pm

Maximizing Ambulatory Potential in Spina Bifida
Samuel Rosenfeld, MD
2:40 pm - 2:48 pm

Discussion
2:48 pm – 3:00 pm

General Care Issues Breakout Session
1:00 pm – 3:00 pm
Location: Commodore A
The Experience of Families with Children with Spina Bifida who Underwent Prenatal Surgery
Ryan Antiel, MD, MA, MSME
1:00 pm - 1:15 pm

Parental Perceptions of Video Education for Spina Bifida in the Neonatal Intensive Care Unit and at Discharge
Lori Howell, DNP, RN, MS
1:15 pm - 1:30 pm

Sociodemographic Characteristics, Health Literacy and Care Compliance in Families with Spina Bifida
Daryl McLeod, MD, MPH
1:30 pm - 1:45 pm

Depressive Symptoms in Parents of Children with Spina Bifida: A Review of the Literature
Monique Ridosh, PhD, RN
1:45 pm - 2:00 pm

Assessment of the Impact of Medical Condition on Families of Adolescents with Spina Bifida
Brandon Rocque, MD, MS
2:00 pm - 2:15 pm

Crawling Onset Facilitates Spatial Cognition in Infants with Lumbar Spina Bifida
Monica Rivera, PT, MS, DPTSc
2:15 pm - 2:30 pm

A Model for the Process of Task Performance to Explain Difficulties’ in Daily Life in Persons with Spina Bifida
Marie Peny-Dahlstrand, PhD
2:30 pm - 2:45 pm

Discussion
2:45 pm – 3:00 pm

Afternoon Break with Poster Viewing
3:00 pm – 3:30 pm
Location: Pavilion

Neurosurgery Breakout
3:30 pm – 6:00 pm
Commodore B

Hydrocephalus Based Procedures in an Adult/Transition Spina Bifida Clinic: A 5-year Experience
Jeffrey Blount, MD
3:30 pm - 3:45 pm

Long-Term Clinical Outcomes of Terminal Myelocystocele
Robin Bowman, MD
3:45 pm - 4:00 pm

Limited Dorsal Myeloschisis’ Association with Dermoids
Sebastian Eibach, MD
4:00 pm - 4:15 pm
The Xiao Procedure did not Improve Continence or Voiding in Children with Spina Bifida: A Summary of Neurologic and Urologic Outcomes of a Randomized, Prospective, Double Blinded Surgical Trial
Gerald Tuite, MD
4:15 pm - 4:30 pm

New Cellular and Molecular Aspects of "Symptomatic" Lipomyelomeningoceles (LMMC): Histological and Molecular Analyses of an Institutional Case Series
Gesa Cohrs, MD
4:30 pm - 4:45 pm

Does Inflammation Play a Role in Tethered Cord Syndrome after MMC-repair Surgeries?
Friederike Knerlich-Lukoschus, PD
4:45 pm - 5:00 pm

Pro-Inflammatory/-apoptotic and Neuroprotective Mediators in the Myelomeningoceles (MMC) Placodes: Potential New Targets in Repair Strategies?
Friederike Knerlich-Lukoschus, PD
5:00 pm - 5:15 pm

Discussion
5:15 pm – 6:00 pm

Urology Breakout Session
3:30 pm – 6:00 pm
Location: Commodore E

Factors Contributing to Stone Formation in Myelomeningocele in those with and without Bladder Augmentation
Travis Atchley, BS
3:30 pm - 3:36 pm

A Novel Predictor for Stone Free Rates After Percutaneous Stone Surgery in Spina Bifida Patients
Rajeev Chaudhry, MD
3:36 pm - 3:42 pm

Practice Patterns for Management of Spina Bifida Patients with Urinary Stones – Single Institutional Experience
Rajeev Chaudhry, MD
3:42 pm - 3:45 pm

Discussion
3:45 pm – 3:50 pm

Bladder Deterioration Following Bladder Outlet Procedure without Enterocystoplasty in Spina Bifida: Need for Extended Follow Up
Brian VanderBrink, BS, MD
3:50 pm - 3:56 pm

Bladder Reconstruction Rates Are Significantly Different Among National Spina Bifida Patient Registry Centers
Johnathan Routh, MD, MPH
3:56 pm - 4:02 pm

Robotic-Assisted Lower Urinary Tract Reconstruction in Spina Bifida Patients with Previous Abdominal Surgery
Effect of Bladder Reconstruction on VP Shunt Failure Rates in Spina Bifida
Dani Gonzalez, MD
4:05 pm - 4:08 pm

Modified Technique of Triamcinolone Injection for the Treatment of Continent Catheterizable Channel Stomal Stenosis: Optimizing Results and Reducing Cost of Care
Brian VanderBrink, BS, MD
4:08 pm - 4:12 pm

Incontinent Urinary Diversion in Young Adult Spina Bifida Patients
Erin McNamara, MD, MPH
4:12 pm - 4:18 pm

Dextranomer Endoscopic Injections for the Treatment of Neuropathic Urinary Incontinence: Evaluation of the Supra Pubic Approach
Ilona Alova, MD
4:18 pm - 4:24 pm

The Role of Robotic Surgery in Complex Surgical Reconstruction of Neurogenic Bladder in Myelomeningocele Patients: Comparison of Open versus Robotic Approach
Laura Cornwell, MD
4:24 pm - 4:27 pm

Lee Hugar, MD
4:27 pm - 4:30 pm

Discussion
4:30 pm – 4:45 pm

Special Lecture
4:45 pm – 5:05 pm

Discussion
5:05 pm – 5:15 pm

Urologic Outcomes in Spina Bifida Patients Undergoing Transitional Care
Jubilee Tan, MD
5:15 pm - 5:21 pm

Sexual Activity and Function of Adult Men with Spina Bifida
Konrad Szymanski, MD, MPH
5:21 pm - 5:27 pm

Pregnancy in Spina Bifida: Implications for Transitional Care
Courtney Shepard, MD
5:27 pm - 5:33 pm

Incidence and Management of Pelvic Organ Prolapse in Adult Spina Bifida Patients
Stephanie Kielb, MD
5:33 pm - 5:39 pm

Factors Associated with Transition from Caregiver to Self Clean Intermittent Catheterization in Spina Bifida
Travis Atchley, BS
5:39 pm - 5:42 pm

Healthcare Provider Experiences in Transitioning Spina Bifida Patients from Pediatric to Adult Care
Kimberly Slocombe, CNP
5:42 pm - 5:45 pm

Discussion
5:45 pm – 6:00 pm

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Nutrition / Bone Health / Obesity Breakout Session
3:30 pm – 6:00 pm
Location: Commodore A

Influence of Loading on Bone in Independently Ambulatory Children with Myelomeningocele
Deirdre Ryan, MD
3:40 pm - 4:00 pm

The Implication of Total Energy Expenditure on Nutritional Guidance in Children with Special Needs
Michele Polfuss, PhD, RN, CPNP-AC/PC
4:00 pm - 4:20 pm

Quantitative Analysis of Lower Extremity Adipose Tissue Distribution in Children with Myelomeningocele
Alexander Van Speybroeck, MD, MPH
4:20 pm - 4:45 pm

Break
4:45 pm – 5:00 pm

Parental Feeding Behaviors and Weight-Related Concerns in Children with Special Needs
Michele Polfuss, PhD, RN, CPNP-AC/PC
5:00 pm - 5:20 pm

Biopsychosocial Model of Care for Nutrition in Children with Spina Bifida
Veronica Meneses, MD, MSHS
5:20 pm - 5:40 pm

Consistency of Weight and Height Measurement in Clinics from the National Spina Bifida Patient Registry (NSBPR)
Julia Alba
5:40 pm - 6:00 pm

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General Care Issues Breakout Session
3:30 pm – 6:00 pm
Location: Britannia/Cambria
The Swedish Myelomeningocele Follow-Up Program (MMCUP)
Ann Alriksson-Schmidt, PhD, MSPH
3:30 pm - 3:45 pm

Clinic Passport to Improve Patient and Caregiver Satisfaction During a Multidisciplinary Clinic
Sarah Rohr, MSN, RN, FNP-C
3:45 pm - 4:00 pm

Developing a Community Based Service Model: Making Evidence Informed Decisions by Listening to the Voices of Adults and Children with Spina Bifida and Hydrocephalus (SBH), their Families and Health Professionals.
Katrina Collins BA, PhD
4:00 pm - 4:15 pm

Mobile Technology to Facilitate Health and Independence among Individuals with Disabilities: Overview of the University of Michigan Rehabilitation Engineering Research Center
Michelle Meade, PhD
4:15 pm - 4:30 pm

Did you Look: Healthy Skin Starts with You a Care Bundle to Promote Healthy Skin in People with Spina Bifida
Patricia Beierwaltes, DNP
4:30 pm - 4:45 pm

Impact of Motor Level and Spinal Curvature on Pulmonary Function in Spina Bifida
Theresa Crytzer, DPT, ATP
4:45 pm – 5:00 pm

Fasting Serum Blood Measures of Bone and Lipid Metabolism in Children with Myelomeningocele for Early Detection of Cardiovascular and Bone Fragility Risk Factors
Alexander Van Speybroeck, MD, MPH
5:00 pm – 5:15 pm

Risk Factors for Advanced Skeletal Maturity in Children and Adolescents with Myelomeningocele
Alexander Van Speybroeck, MD, MPH
5:15 pm – 5:30 pm

Discussion
5:30 pm – 6:00 pm

Saturday, March 18, 2017

Breakfast
Location: Commodore Foyer
7:00 am – 7:30 am

Overview Highlights from Previous Day’s Sessions
Location: Commodore C,D,&E
7:30 am – 8:00 am

Panoramic View of Latin America Contribution in Spina Bifida
Location: Commodore C,D&E
8:00 am – 9:30 am

Speakers: Lic. Federico Nuñez, Leyla Camarillo, MD, Rosa Andrea Pardo, MD, Ana Jiménez, MD, Gaston Valverde, MD, Laura Martinez, MD

Speakers: Lic. Federico Nuñez, Leyla Camarillo, MD, Rosa Andrea Pardo, MD, Ana Jiménez, MD, Gaston Valverde, MD, Laura Martinez, MD
This session will highlight various aspects of Spina Bifida care and prevention in Latin America, including the role of civic organizations, epidemiology, folic acid fortification efforts, clinical care and connecting professionals together to provide and improve care.

**Public Health Perspectives on Neural Tube Defects: Genetics, Genomics and Applied Epidemiology**
9:30 am – 10:30 am
Location: Commodore C,D&E

*Speakers:* Philip J. Lupo, PhD, MPH, Krista Stimson Crider, PhD

This session will focus on “genetic susceptibility to neural tube defects: where are we, where should we be going” which will be discussed by Dr. Lupo, while Dr. Crider will be discussing “preventing neural tube defects: How do determine when all folate sensitive neural tube defects have been prevented?”

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**Morning Break**
Location: Commodore Foyer
10:30 am – 10:45 am

**Adults with Spina Bifida Speak Out: Healthcare Through the Lifespan**
10:45 am – 12:15 pm
Location: Commodore C,D&E

*Speakers:* Julie Yindra, Matthew Davis, Kathy Price-Toby, Mark Deschamp

This panel of adults with Spina Bifida will talk about their own health care experiences as adults, including some aspects of aging with Spina Bifida, challenges of obtaining good health care as adults, speaking about the challenges of disjointed/uncoordinated health care as we have aged. They will also speak about the lack of knowledge/lack of preparation in primary health care to meet the needs of adults with complex conditions like Spina Bifida. They will also present thoughts regarding what health care providers can do to improve care.

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**Boxed Lunch, Poster Viewing, Exhibitors**
Location: Pavilion
12:15 pm – 1:30 pm

**Transition / Adult Care Breakout Session**
1:30 pm – 3:30 pm
Location: Commodore E

**Evaluation of Spina Bifida Transitional Care Practices in the US**
Maryellen Kelly, DNP, CPNP, MSN
1:30 pm - 1:45 pm

**A Transition Protocol at Children’s Hospital of Pittsburgh of U pmC**
Unoma Akamagwuna, MD
1:45 pm - 2:00 pm

**2016 NEO SBA Adult Ed Day: Building a Transition Collaborative for SB Y and YA to Create Seamless Access to Adult Based Services**
Suzanne Fortuna, MSN, RN, APRN-BC, CNS, FNP
Physical Activity / Participation Breakout Session
1:30 pm – 3:30 pm
Location: Commodore A

Introduction
Amy Houtrow, MD, PhD, MPH
1:30 pm – 1:35 pm

Physical Behavior is Associated with Age and Ambulatory Status, but Not with Gender or VO2peak in Wheelchair-using Youth with Spina Bifida.
Manon Bloemen, MSc
1:35 pm - 1:50 pm

Can Initial Assessment Findings Predict Future Mobility of Children with Spina Bifida?
Antoinette Botman
1:50 pm - 2:05 pm

Using Initial Physical Assessment Findings, it is Possible to Predict the Age a Child with Spina Bifida will Commence Independent Walking: A Retrospective Chart Audit
Antoinette Botman
2:05 pm - 2:20 pm

Walking Activity in Children with Myelomeningocele
Deirdre Ryan, MD
2:20 pm - 2:35 pm

Break
2:35 pm – 2:40 pm

Adaptive Design: Cardboard Equipment Solutions for Toddlers with Spina Bifida
Nienke Dosa, MD, MPH
2:40 pm - 2:55 pm
Nontraditional Medicine
Anna Graham, BS
2:55 pm - 3:10 pm

Determinants of Physical Activity Participation in Adults with Spina Bifida
Kerri Vanderbom, BA, MA, PhD
3:10 pm - 3:25 pm

Discussion and Questions
3:25 pm – 3:30 pm

Psychosocial / Quality of Life Issues Breakout Session
1:30 pm – 3:30 pm
Location: Commodore B

Sexual Identity and Orientation in Adult Men and Women with Spina Bifida
Konrad Szymanski, MD, MPH
1:30 pm - 1:45 pm

Patient and Parental Stress with Spina Bifida
Ratcharin Kongkasuwan, MD
1:45 pm - 2:00 pm

Subjective Quality of Life for Youth with Spina Bifida
Karen Lowry, BS, MS
2:00 pm - 2:15 pm

Discrepancies in Quality of Life Reported by People with Spina Bifida and their Caregivers
Konrad Szymanski, MD, MPH
2:15 pm - 2:30 pm

Pain and Spina Bifida: Common, Severe, and Worse with Age
Konrad Szymanski, MD, MPH
2:30 pm – 2:45 pm

Parental Perceptions of Video Education for Spina Bifida in the Neonatal Intensive Care Unit and at Discharge
Lori Howell, DNP, RN, MS
2:45 pm - 3:00 pm

Use of a Gaming App to Promote Self-management of Spinal Cord Dysfunction
Michelle Meade, PhD
3:00 pm – 3:15 pm

Estimation of Health State Utility Values for Spina Bifida Using an Online Platform
Jonathan Routh, MD, MPH
3:15 pm - 3:30 pm

Genetics / Epidemiology Breakout Session
1:30 pm – 3:30 pm
Location: Britannia / Cambria
Lijing Ouyang, BA, MA, PhD
1:30 pm – 1:45 pm

The Inspiring Tale of Infant Survival of Spina Bifida, a Historical Perspective
Nelson Pace, PhD
1:45 pm - 2:00 pm

Surveillance Survey of Family History in Children with Neural Tube Defects
Betsy Hopson, MSHA
2:00 pm - 2:15 pm

Longitudinal Study of Bladder and Bowel Continence among Spina Bifida Patients in the National Spina Bifida Patient Registry (NSBPR)
Tiebin Liu, BS, MSPH
2:15 pm - 2:30 pm

Age Distribution of Surgical Procedures and Health Outcomes in the National Spina Bifida Patient Registry (NSBPR)
John Wiener, MD, FACS, FAAP
2:30 pm – 2:45 pm

Estimating the Economic Impact of Spina Bifida in the United States
Jonathan Routh, MD, MPH
2:45 pm - 3:00 pm

Lifetime Costs of Care for Infants Born with Spina Bifida in the United States
Lijing Ouyang, BA, MA, PhD
3:00 pm – 3:15 pm

Discussion & Questions
3:15 pm – 3:30 pm

Afternoon Break
3:30 pm – 3:45 pm
Location: Commodore Foyer

Transition / Adult Care Breakout Session
3:45 pm – 6:00 pm
Location: Commodore E

Perceptions of Healthcare by Adults with Spina Bifida
Monica Still, RN, BSN
3:45 pm - 4:00 pm

Self-Management in Spina Bifida: A Synthesis of the Literature
Kathleen Sawin, RN, PCNP-PC
4:00 pm - 4:15 pm

Pain and Health Status in Adults with Myelomeningocele Living in Southern Sweden
Ann Alriksson-Schmidt, PhD, MSPH
4:15 pm - 4:30 pm
Effectiveness of a Wellness Program for Individuals with Spina Bifida and Spinal Cord Injuries within an Integrated Delivery System
Brad Dicianno, MD
4:15 pm - 4:30 pm

Spina Bifida in Iceland: Epidemiology, Health and Well-being Among Adults
Marrit Meintema, BSc, MSc
4:30 pm - 4:15 pm

Feasibility of Using Mobile Health to Promote Self-management in Spina Bifida
Brad Dicianno, MD
4:30 pm - 4:45 pm

Physical Activity / Participation Breakout Session
3:45 pm – 6:00 pm
Location: Commodore A

Introduction
Amy Houtrow, MD, PhD, MPH
3:45 pm – 3:50 pm

Field-testing the Pediatric Neuromuscular Recovery Scale in Children with Spina Bifida
Elizabeth Ardolino, PT, PhD
3:50 pm - 4:05 pm

Validity and Reliability of Skill-related Fitness Tests for Wheelchair-using Youth with Spina Bifida
Manon Bloemen, MSc
4:05 pm - 4:20 pm

Developmental Wheelchair Mobility Skills in Spinal Defects
Pamela Wilson, MD
4:20 pm - 4:35 pm

Validity of a Wheelchair Perceived Exertion Scale (WHEEL Scale) for Arm Ergometry Exercise in People with Spina Bifida
Theresa Crytzer, DPT, ATP
4:35 pm - 4:50 pm

Break
4:50 pm – 5:00 pm

Personal and Environmental Factors to Consider when Aiming to Improve Physical Activity in Youth with Spina Bifida
Manon Bloemen, MSc
5:00 pm - 5:15 pm

Exercise Prescription Using a Group Normalized Rating of Perceived Exertion in Adolescents and Adults with Spina Bifida
Theresa Crytzer, DPT, ATP
5:15 pm - 5:30 pm

Adapted, Inclusive, Exclusive, or Segregated PE: What is Wrong with this Picture?
Kerri Vanderbom, BA, MA, PhD
5:30 pm - 5:45 pm
Prevalence of Chronic Constipation in Infants with Spina Bifida
Gene Huang, PhD
3:45 pm - 3:48 pm

Using a Decision Tree to Guide Bowel Management in Spina Bifida
Patricia Beierwaltes, DNP
3:48 pm - 3:54 pm

Bowel Management for Spina Bifida: An Unofficial Guide by and for Parents and Adults with SB
spinabifidabowelmanagement.com
Colleen Payne
3:54 pm - 3:57 pm

Factors Associated with Bowel Continence in a Pediatric Spina Bifida Clinic
Richard Drew Davis, MD
3:57 pm - 4:00 pm

Discussion
4:00 pm – 4:10 pm

Dedicated Neurogenic Bowel Provider within a Multidisciplinary Myelomeningocele Clinic: Is there an Advantage?
Betty Jo Manz, MSN, CPNP
4:10 pm - 4:13 pm

A Quality Improvement Nursing Intervention for Neurogenic Bowel Management in the Texas Children's Spina Bifida Clinic
Rhonda Bolin, BSN, RN, CPN
4:13 pm - 4:16 pm

Can Transanal Irrigations Prevent Surgery and Improve Quality of Life in Patients with Organic Defecatory Disorders?
Fiona Pau, DNP, RN, CPNP
4:16 pm - 4:22 pm

Efficacy of Peristeen Transanal Irrigation System for Neurogenic Bowel in the Pediatric Population
Tiffany Gordon, MSN, RN, CRRN, CPN
4:22 pm - 4:25 pm

Discussion
4:25 pm - 4:35 pm

Differences in Continence Rates in Individuals with Spina Bifida Based on Ethnicity
Kathryn Smith RN, MN, DrPH
4:35 pm - 4:41 pm

Age of Transition to Self Clean Intermittent Catheterization in Patients with Spina Bifida
Travis Atchley, BS
Factors Related to Parent and Child Satisfaction with Bladder and Bowel Programs in Children with Spina Bifida in the National Spina Bifida Patient Registry (NSBPR)
Kathleen Sawin, RN, PCNP-PC
4:47 pm - 4:53 pm

Urinary Management and Continence Outcomes of Adults with Spina Bifida and Comparison to Children: Findings of National Spina Bifida Patient Registry (NSBPR)
John Wiener, MD, FACS, FAAP
4:53 pm - 4:59 pm

Bowel Management and Continence Outcomes of Adults with Spina Bifida: Findings of National Spina Bifida Patient Registry (NSBPR)
John Wiener, MD, FACS, FAAP
4:59 pm - 5:05 pm

Bowel Incontinence in Adults with Spina Bifida
Danielle Powell, MD
5:05 pm - 5:11 pm

Variation in Surgical Management of Neurogenic Bowel among Centers Participating in National Spina Bifida Patient Registry
Jonathan Routh, MD, MPH
5:11 pm - 5:17 pm

Discussion
5:17 pm – 6:00 pm

Neuropsychology / Learning Breakout Session
3:45 pm – 6:00 pm
Location: Britannia / Cambria

Early Cognitive Development in Spina Bifida
Rebecca Elliott
3:45 pm - 4:00 pm

Neuropsychological Performance of Preschool Children with Spina Bifida (SB)
Katherine Ong, BS, MA, PhD
4:00 pm - 4:15 pm

Developmental Outcomes by Hydrocephalus and Shunting Status for MOMS Subjects Status Post Prenatal Repair
Amy Houtrow, MD, PhD, MPH
4:15 pm - 4:30 pm

Daily Time Management in Children with Spina Bifida
Marie Peny-Dahlstrand, PhD
4:30 pm - 4:45 pm

Cognition in Spina Bifida and its Consequences in Daily Life - A Life-span Perspective. A Systematic Review
Barbro Lindquist, PhD
4:45 pm - 5:00 pm
Can the Cognitive Orientation to Daily Occupational Performance (CO-OP) Approach Enhance Executive Functions and Participation in Young Adults with Spina Bifida – A Multiple Case Study  
Marie Peny-Dahlstrand, PhD  
5:00 pm - 5:15 pm

Developing a Systematic Neurodevelopmental Monitoring Program for Infant and Toddlers with Spina Bifida: Why Is it Important?  
Jennifer Queally, PhD  
5:15 pm - 5:30 pm

Discussion and Questions  
5:30 pm – 6:00 pm

Networking Reception  
Location: Marina Terrace  
6:30pm – 8:00pm

Sunday, March 19, 2017

Breakfast  
Location: Commodore Foyer  
7:00 am – 7:30 am

Overview Highlights from Previous Day’s Sessions  
Location: Commodore C,D,&E  
7:30 am – 8:00 am

Trauma Informed Approach to Youth with Spina Bifida  
Location: Commodore C,D&E  
8:00 am – 8:45 am

Speakers: Natalie C. Cruz, Psy.D and Veronica Meneses, MD, MSHS

This plenary session will identify risk factors for trauma in the population of youth with Spina Bifida utilizing a developmental framework, highlight potential consequences of trauma for health and well-being from a bio-psycho-social perspective, outline a trauma-informed approach to include both definition and application to youth with Spina Bifida, outline examples of trauma-related needs among youth with Spina Bifida and describe appropriate, evidence-based interventions, and provide the participants with relevant resources and agencies for use and support.

Self-Management in Spina Bifida: Current Evidence and Improving Outcomes  
Location: Commodore C,D&E  
8:45 am – 10:00 am

Speakers: Kathleen Sawin, PhD, CPNP-PC, FAAN, Cecily Betz, PhD, RN, FAAN, and Brad Dicianno, MD

Building skills of self-management is critical for optimal success in adulthood. This session will discuss the theoretical understanding of self-management, what we know about the self-management in Spina Bifida, and seek to provide information of components of programs, approaches, or interventions to improve patient empowerment and self-management in Spina Bifida.
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<tr>
<th>Event</th>
<th>Time</th>
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<tbody>
<tr>
<td>Morning Break</td>
<td>10:00 am – 10:15 am</td>
<td>Commodore Foyer</td>
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<tr>
<td>Awards Papers</td>
<td>10:15 am – 10:30 am</td>
<td>Commodore C,D&amp;E</td>
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<tr>
<td>Lifetime Achievement Award Speakers</td>
<td>10:30 am – 11:30 am</td>
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<tr>
<td>Carla Verpoorten, MD</td>
<td>10:30 am – 11:00 am</td>
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<tr>
<td>Luciano Dias, MD</td>
<td>11:00 am – 11:30 am</td>
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At the World Congress this year, two outstanding physicians are being honored with Lifetime Achievement Awards for their long and distinguished careers, which have had a particular focus on care and research related to Spina Bifida. Each speaker will give a presentation about their careers, interest in Spina Bifida and their contributions to improving care related to Spina Bifida.

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<tr>
<th>Event</th>
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<tr>
<td>Hal Pote Lectureship Speaker</td>
<td>11:30 am – 12:00 pm</td>
<td>Commodore C,D&amp;E</td>
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<tr>
<td>Speaker</td>
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<td>Douglas Sorocco, Esq.</td>
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Hal Pote was a tireless advocate for people with Spina Bifida and gave his time, energy and money, to improve the lives of people with Spina Bifida. Mr. Sorocco is this year’s Hal Pote Lectureship speaker. Mr. Sorocco is an attorney, former member and chair of the Spina Bifida Association Board of Directors, and an adult with Spina Bifida.

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<td>Closing Remarks</td>
<td>12:00 pm -12:15 pm</td>
<td>Commodore C,D&amp;E</td>
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