

THE **FUTURE IS NOW**
FIRST WORLD CONGRESS
ON SPINA BIFIDA
RESEARCH AND CARE
MARCH 15-18, 2009



Nursing and Allied Health Breakout Sessions
Monday, March 16, 2009
1:45 pm – 6:30 pm

1:45 – 1:50 pm

Welcome

Mary Jo Dunleavy, BSN, RN
Karen Rauen, MSN, RN, BCIAC-PMDB

Discussion Facilitator: Lori Lowe, MSN, RN, CPNP-PC

1:50 – 2:50 pm

Childhood Transitions

1:50 – 2:00 pm

A Family Intervention to Enhance Involvement in Condition Management of Youth with Spina Bifida (Rachel Neff Greenley, PhD)

2:00 – 2:10 pm

A Developmental Approach to Managing Bladder Incontinence (Jean Brown, MS, APRN)

2:10 – 2:20 pm

The Process of Transition of Care of the Neurogenic Bowel Management in the Pre-adolescent with Spina Bifida; The Primary Caregiver's Perspective (Patricia Braun, RNC, CPNP, PhD)

2:20 – 2:30 pm

Testing the Transition Training Preparation Program (Kathryn Smith, RN, MN)

2:30 – 2:40 pm

The Experience of Self-management in Transition-age Women Living with Spina Bifida (Melissa Bellin, PhD, MSW, LCSW)

2:40 – 2:50 pm

Toward Authentic Care and Transparency of the Other (Christine Kinavey, PhD)

2:50 – 3:20 pm

Open Discussion (Lori Lowe, MSN, RN, CPNP-PC, Facilitator)

3:20 – 3:25 pm

Summary of Key "Take-home" Themes (Karen Rauen, MSN, RN, BCIAC-PMDB)

3:25 – 3:30 pm

Poster Presenters' Quick Overview*

3:30 – 4:30 pm

Coffee Break with Poster Rounds

4:30 – 5:30 pm Promoting Positive Outcomes for People with Spina Bifida and Families

4:30 – 4:40 pm *Current Prevalence of Latex Sensitization in Children with Spina Bifida with Use of Latex Precautions* (Eric Levey, MD)

4:40 – 4:50 pm *The Development of Lower Extremity Skin Evaluation and Educational Tools Based on a Nationwide Survey of Spina Bifida Clinics* (Laura Gueron, PT, MPH)

4:50 – 5:00 pm *The Use of an Instructional Skin Care DVD for Those with Spina Bifida or SCI: Is There an Effect on Knowledge and Behavior?* (Laura Gueron, PT, MPH)

5:00 – 5:10 pm *Use of a Cone Irrigation Enema for Bowel Continence in Spina Bifida* (Jean Brown, MS, APRN)

5:10 – 5:20 pm *Sexuality for Young Adults with Spina Bifida.* (Susan Labhard, MSN, RN)

5:20 – 5:30 pm *The Impact of Spina Bifida and Other Chronic Health Conditions (CHC) on Families* (Karen Rauen, MSN, RN, BCIAC-PMDB)

5:30 – 6:10 pm Open Discussion (Lori Lowe, MSN, RN, CPNP-PC, Facilitator)

6:10 – 6:15 pm Summary of Key "Take Home" Themes (Mary Jo Dunleavy, BSN, RN)

6:15 – 6:30 pm Closing Remarks

Posters*

- *Family Management of a Chronic Condition: Perspectives of Adolescents with Spina Bifida* (Kathy Sawin, DNS, CPNP, FAAN; Josanne Wollenhaupt, RN, MSN)
- *The Effectiveness of Antegrade Continence Enema (ACE) Procedures on Toileting Independence in the Pediatric Spina Bifida Population* (Drew Davis, MD)
- *Pressure Ulcer Risk Factors in Children and Adolescents with Spina Bifida and Spinal Cord Injuries* (Patricia Beierwaltes, CPNP)
- *Mentoring Projects for Teens with Spina Bifida Result in Improved Socialization Skills, Independence and Community Participation* (Karen Rauen, MSN, RN, BCIAC-PMDB)
- *A Unique Outreach Effort to Unite Teens with Spina Bifida, Geographically Distant from the Metro Area, with Mentors Was Successful and Can Be Readily Applied to All States* (Karen Rauen, MSN, RN, BCIAC-PMDB)