



Spina Bifida Clinical Care Meeting June 4-5, 2021

**Children's Hospital of Philadelphia, Pennsylvania
Spina Bifida Association, Virginia**

All times are in Eastern Standard Time

Friday June 4, 2021

Welcome 11:00 – 11:05 AM

Timothy Brei, MD
Medical Director
Spina Bifida Association
Professor, Neurodevelopmental Pediatrics
Seattle Children's Hospital
Adult with Spina Bifida

SBA Updates 11:05 - 11:30PM

Sara Struwe
President and CEO
Spina Bifida Association

Announcement, SBA Clinic Care Partners 11:30 – 12:00 PM

2021 Application Process
Partnership Update/Renewal Process

Judy Thibadeau, RN MN
Director of Research and Services
Spina Bifida Association

Improving How We Care 12:00 – 12:45 PM

The Family/Adult Experience

Facilitator, Jason Woodward, MD
Cincinnati Children's Hospital Medical Center
Division of Adolescent and Transition Medicine

Description: Panel of adults and parents expressing how their clinic experiences have been helpful; how they've been challenging

Objectives:

- Describe SB clinic processes/practices that support families and adults to achieve desired outcomes

- Describe SB clinic processes/practices that inhibit the achievement of desired outcomes
- Demonstrate understanding of importance of Knowledge of patient's/family's clinic experience

Break

12:45 – 1:00 PM

Achieving Desired Outcomes using a Group Visit Approach

1:00 – 1:45 PM

Nienke Dosa, MD

Professor of Pediatrics

Center for Development, Behavior and Genetics

Upstate Healthcare Center

Description: Using Group Visits in a Spina Bifida Clinic

Objectives:

- List topics that may benefit from the group visit format in a Spina Bifida Clinic
- Describe how group visits can facilitate goal directed behavior
- Describe the experience in Syracuse using the group visit format to yield more interest in activities that promote fitness

The Neurocognitive Profile in Spina Bifida & Implications on Care

1:45 – 2:30 PM

Julie Yindra, M.Ed.

Director, Student Access Services, Hofstra University, New York

Adult with Spina Bifida

Jane Schreiber, PhD

Pediatric Neuropsychologist

Department of Child & Adolescent Psychiatry and Behavioral Sciences

The Children's Hospital of Philadelphia

Timothy Brei, MD

Medical Director

Spina Bifida Association

Professor, Neurodevelopmental Pediatrics

Seattle Children's Hospital

Adult with Spina Bifida

Description: Presentation about neuropsychology in Spina Bifida

Discussion with neuropsychologist and adults with Spina Bifida describing their life experiences that were/are challenging because of the way their brains function

Objectives:

- Describe characteristics of the Spina Bifida brain
- Describe approaches to successfully navigate life with the challenges of the Spina Bifida brain

Breakout Sessions

2:30 – 4:00 PM

1. Clinic practices to promote decision making, transition preparation, and ways to address challenges to developing self-sufficiency

Panel:

Ellen Fremion, MD

Assistant Professor of Internal Medicine and Pediatrics
Baylor College of Medicine Texas Medical Center

Richard Adams, MD

Professor and Division Director of Developmental Behavioral Pediatrics
University of Texas Southwestern Medical Center
Medical Director of Pediatric Developmental Disabilities
Texas Scottish Rite Hospital for Children

Betsy Hopson, MSHA

Director and Coordinator of the Spina Bifida Program
Children's of Alabama
University of Alabama at Birmingham

Shannon Bevans, MSW

Adult Transition Care Coordinator – Spina Bifida
Orlando Health Arnold Palmer Hospital for Children

Description: Join this panel session for opportunity to discuss tools and tips to facilitate the development of decision making in people with Spina Bifida beginning at a young age; how to address the challenges to develop self-sufficiency; and examples of the use of transition readiness data to support the transition preparation effort

2. Spina Bifida Clinics, a Philosophy of Care-Creative Ways to Deliver; Guideline Implementation

Facilitators:

Kathryn Smith, RN, MN DrPH

Associate Professor Clinical Pediatrics Keck School of Medicine of USC
Children's Hospital Los Angeles

William Walker, MD

Robert A. Aldrich Professor of Pediatrics
University of Washington School of Medicine

Chief, Division of Developmental Medicine,
Seattle Children's Hospital

Description: Join this panel session for a discussion of the different ways Spina Bifida care can be delivered, including financial considerations, and challenges to implementing the Guidelines for the Care of People with Spina Bifida with examples of approaches that have proven successful

3. Legal issues of "adulthood" related to medical care. Don't be afraid to plan; be afraid if you don't plan...

Andre Sam, CRPC®, APMA
SilverState Disability & Special Needs Planning
Las Vegas, NV
asam@projectdsnp.com
(801)844-9684

Description: Join this session for an informative and educational workshop for both health care professionals who work with, as well as family members who have loved ones of all ages with Spina Bifida or any other physical and/or intellectual disabilities or special needs. The topics covered in this workshop include guardianship & alternatives to guardianship, wills, family trusts, special needs trusts, Microboards, SSI, Social Security Retirement/Survivor Benefits, Social Security Disability, Medicaid/Medicare, ABLE Accounts, budget and transition planning. For health care professionals, this workshop will help you understand the basics of planning for yourselves and your families, and explain why these planning aspects are important for families to be aware of and help you identify where you can bring these topics up in conversation in your relationships with families. For parents and caregivers, this workshop will explain why these planning aspects are important to have and how they complement each other in a plan designed to protect yourself, your family and/or your loved ones' current and future quality of care and life.

Reception & Awards 4:00 – 4:30 PM

Adjourn

Spina Bifida Care at Children's Hospital of Philadelphia 4:35 – 4:40 PM
Virtual tour of Children's Hospital of Philadelphia.

Debrief Q&A for nonclinical community members 4:45 PM

Judy Thibadeau, RN, MN
National Director of Research & Services

Do you have questions about the day? Join Judy Thibadeau, RN, MN, National Director of Research & Services at SBA, for a debrief Q&A of the day for nonclinical community members.

Saturday June 5, 2021

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| Successes and Challenges Danielle Nicholson, DO | 11:00 – 11:30 AM |
| MOMS Update Amy Houtrow, MD, PhD, MPH Professor of Physical Medicine and Rehabilitation and Pediatrics Endowed Chair for Pediatric Rehabilitation Medicine UPMC Department of Physical Medicine and Rehabilitation Division Chief of Pediatric Rehabilitation Medicine UPMC Children’s Hospital of Pittsburgh | 11:30 – 12:00PM |
| <ul style="list-style-type: none">• Understand the impact of fetal surgery in the MOMS trial on hydrocephalus cognition• Review the physical functioning outcomes after fetal surgery in MOMS• Discuss post-MOMS interventions | |
| SBA Catheter Survey Dawne Widener-Burrows Widener Research, LLC Maryellen Kelly, DNP Duke Health | 12:00 – 12:30PM |
| Break | 12:30 – 12:45 PM |
| <u>Breakout Sessions, repeated</u> | 12:45 – 2:15 PM |
| <ol style="list-style-type: none">1. Clinic Practices to promote decision making, transition preparation, and how to address challenges to developing self-sufficiency2. Spina Bifida Clinics, a Philosophy of Care-Creative Ways to Deliver; Guideline Implementation3. Legal issues of “adulting” related to medical care Don’t be afraid to plan; be afraid if you don’t plan | |
| Patient Centered Care, Patient Engagement Eleanor Perfetto, PhD, MS Executive Vice President of Strategic Initiatives National Health Council | 2:15 – 2:45 PM |

Closing Remarks

2:45 – 3:00 PM

Sara Struwe

President and CEO

Spina Bifida Association

Debrief Q&A for nonclinical community members

3:15 PM

Judy Thibadeau, RN, MN

National Director of Research & Services

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