



SPINA BIFIDA
ASSOCIATION

**Spina Bifida Clinical Care Meeting
Boston Children's Hospital
June 3-5, 2022**

Agenda

FRIDAY, JUNE 3, 2022

Opening Reception

6:00 PM–8:00 PM

SATURDAY, JUNE 4, 2022

Welcome

Timothy Brei, MD

8:30 AM--8:35 AM

- Medical Director, Spina Bifida Association
- Professor, Neurodevelopmental Pediatrics, Seattle Children's Hospital, WA

SBA Updates

Sara Struwe, MPA

8:35 AM–9:00 AM

- President and CEO, Spina Bifida Association

NSBPR Research

Catharine Riley, PhD, MPH

9:00 AM–9:30 AM

- Centers for Disease Control & Prevention, National Center on Birth Defects and Disabilities

**Developing a Program
for the Care of Adults in
Your City**

Karen Cushnyr, MS, ADAC
Adult Advisory Council, Spina Bifida
Association

9:30 AM–10:00
AM

**Spina Bifida Research
Agenda Update**

Brad E. Dicianno, MD

- Associate Medical Director and Chair, Spina Bifida Association Professional Advisory Council
- Associate Professor, Department of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine, PA

10:00 AM–10:30
AM

Alexander Van Speybroeck, MD

- Medical Director, Spina Bifida Program, Children's Hospital Los Angeles, CA
- Co-Director, Residency Program - IMPACT Global Health Track
- Clinical Associate Professor of Pediatrics (Clinician Educator), Keck School of Medicine of USC

Break

10:30 AM–11:00 AM

**Using the Medical
Coding System for Better
Reimbursement**

Peggy McManus, MHS

- Co-Director, Got Transition®
- President, The National Alliance to Advance Adolescent Health

11:00 AM–12:00
PM

Peter Rappo, MD, Retired

- Pediatric Associates of Brockton, West Bridgewater, MA
- Signature Healthcare Brockton Hospital
- South Shore Hospital-South Weymouth
- Chair, National American Academy of Pediatrics Practice Committee
- President and Vice President, Massachusetts Chapter, American Academy of Pediatrics
- President and Vice President, Plymouth District Medical Society

**How to Present Your
Spina Bifida Program to
Get What You Need**

Hans Pohl, MD

- Chief of Urology, Children's National Hospital, Washington, DC

12:00 PM–12:30
PM

**Lunch and Networking
12:30 PM-1:30 PM**

**Endoscopic Third
Ventriculostomy and
Choroid Plexus
Cauterization Procedure
(ETV/CPC)**

Benjamin C. Warf, MD
• Director, Neonatal and Congenital
Anomaly Neurosurgery
• Professor of Neurosurgery,
Harvard Medical School, Boston,
MA

1:30 PM–2:00 PM

**Breakout Sessions
2:00 PM–3:30 PM**

**Break
3:30 PM–3:45 PM**

**Breakout Sessions
3:45 PM–5:15 PM**

Reception and Awards

5:15 PM–6:00 PM

**Adjourn
6:00 PM**

SUNDAY, JUNE 5, 2022

**Boston Children's
Hospital
Successes and
Challenges**

• Boston Children's Spina Bifida
Clinic Staff

8:30 AM–9:00 AM

**How to Integrate
Neuropsychology into
Your Spina Bifida Clinic**

Jennifer Queally, PhD
• Attending Psychologist,
Department of Psychiatry and
Behavioral Sciences
• Assistant Professor of
Psychology, Department of
Psychiatry, Harvard Medical
School, Boston, MA

9:00 AM–9:45 AM

**Care Coordination
Academy: Experiences
of Three Spina Bifida
Clinics**

**National Center for Care
Coordination Assistance
Technical Assistance**

9:45 AM-10:15 AM

Break

10:15 AM-10:45 AM

Breakout Sessions

10:45 AM-12:15 PM

Closing Remarks

12:15 PM-12:30 PM

BREAKOUT SESSIONS

You have opportunity to participate in two of five breakout sessions on Saturday and one of five breakout sessions on Sunday.

- 1. Breakout Session #1: Transition workshop on pieces of the pathway including neuropsychology**
 - Ellen Jean Fremion, MD, Assistant Professor, Department of Medicine, Transition Medicine, Baylor College of Medicine, Houston, TX
- 2. Breakout Session #2: Report on urodynamic studies (UDS) to treat tethered cord and the improvements in bladder function after surgery**
 - Hsin-Hsiao (Scott) Wang, MD, MPH, MBAn, Attending Surgeon, Department of Urology; Director, Computational Healthcare Analytics Program (CHAP); Affiliated faculty, Computational Health Informatics Program (CHIP) Assistant Professor of Surgery, Harvard Medical School, Boston, MA
- 3. Breakout Session #3: Sexuality**
 - John S. Wiener, MD, Director of Pediatric Urology, Professor of Surgery; Professor of Pediatrics, Duke University School of Medicine, Durham, NC
 - Courtney Streur, MD, Clinical Assistant Professor, Urology, Michigan Medicine, MI
- 4. Breakout Session #4: Rehabilitation Medicine and Spina Bifida**
 - Brad Dicianno, MD, Associate Medical Director and Chair, Spina Bifida Association Professional Advisory Council; Associate Professor, Department of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine, PA
- 5. Breakout Session #5: Spina Bifida Clinic and Chapter collaboration**
 - Texas
 - Robin Lee, Spina Bifida Association of North Texas
 - Richard Adams, MD, Medical Director, Pediatric Developmental Disabilities, Scottish Rite for Children; Professor of Pediatrics and Division Director, Developmental Behavioral Pediatrics, UT Southwestern Medical Center
 - Greater New England
 - Jean Berstchmann, Spina Bifida Association of Greater New England
 - Rebecca L. Sherlock, MSN, RN, PPCNP-BC, Advanced Practice Nurse II, Department of Urology; Clinical Coordinator, Center for Spina Bifida, Boston Children's