



2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now

**THURSDAY, MAY 28, 2026**

<p><b>Pre-Conference Workshop: Three Transition Assessment Instruments for Clinical &amp; Research Use (Separate Ticket)</b></p>	
<p><b>5:00 – 7:00 pm</b> <b>Room: Maple</b></p>	<p>The workshop team will consider three clinical/research instruments for transition readiness assessments.</p> <p><b>Facilitators:</b> Ellen Fremion, MD and Betsy Hopson, Ph.D., MSHA</p> <p><b>Presenters:</b> Kathy Sawin, PhD, CPNP-PC, FAAN; Tim Brei, MD; Catherine Stephan, PhD; Camille Wilson, PhD; Betsy Hopson, Ph.D., MSHA</p>



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

**What is Futures Planning?**

**Futures Planning** is the process of creating a comprehensive life plan for an individual, often a child or adult with a disability, to achieve their vision of a good life, focusing on their dreams, preferences, and needs for living arrangements, finances, employment, and social connection. It is a person-centered approach that involves a committed team of family, friends, and professionals who work together to develop strategies and identify resources to support the individual's independence and well-being.

**FRIDAY, MAY 29, 2026**

<p><b>Addresses:</b>          Marriott: 3033 Fairmount St, Dallas, TX 75201          Scottish Rite: 2222 Welborn St, Dallas, TX 75219</p> <p><b>Morning Transport TO Scottish Rite</b>          7:25 AM, 7:45 AM, 8:05 AM</p> <p><b>Breakfast // 7:30 AM - 8:30 AM // Outside of Reverchon</b></p>	
<p><b>PLENARY SESSIONS // 8:30 AM - 12:00 PM</b></p> <p><b>Room: Reverchon</b></p>	
<b>8:30 AM-8:35 AM</b>	<p><b>Welcome and Good Morning</b></p> <ul style="list-style-type: none"> <li>• Tim Brei, Medical Director, Spina Bifida Association</li> </ul>
<b>8:35 AM-8:55 AM</b>	<p><b>SBA’s Approach to Improving Clinical Care and the Spina Bifida Collaborative Care Network</b></p> <ul style="list-style-type: none"> <li>• Sara Struwe, CEO, Spina Bifida Association</li> </ul>
<b>8:55 AM-9:20 AM</b>	<p><b>What We Learned from the SBA Benchmark Project: Using Data to Support Future Success Among People with Spina Bifida.</b></p> <ul style="list-style-type: none"> <li>• Kathy Sawin, PhD, CPNP-PC, FAAN, University of Wisconsin Milwaukee</li> </ul>
<b>9:20 AM-9:50 AM</b>	<p><b>SBA’s Community Centered Research Agenda: Improving Clinical Care</b></p> <ul style="list-style-type: none"> <li>• Introduction: Laura Carlson, PhD, MS - SBA Research Advisory Council Coordinator</li> <li>• Presenters: SBA Research Advisory Council             <ul style="list-style-type: none"> <li>○ Virginia (Ginny) Briggs, PhD</li> <li>○ Maryellen Kelly, DNP, CPNP, MHSc</li> <li>○ Paula Peterson, APRN</li> <li>○ Audrey Roach, RN-BSN, CNRN, CPN</li> <li>○ Hubert S. Swana, MD</li> </ul> </li> </ul>
<p><b>Break / Exhibit Hall Open // 9:50 AM–10:15 AM // (Demonstration Poster Setup)</b></p>	



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

<p><b>10:15 AM-11:00 AM</b></p>	<p><b>Reaching Out and Communicating With our Latino Community – Cultural and Language Considerations.</b></p> <ul style="list-style-type: none"> <li>• Facilitators: Dr. Bordes Edgar and Dr. Karen Dorsman - Division of Developmental Behavioral Pediatrics - UT Southwestern</li> <li>• Presenters:             <ul style="list-style-type: none"> <li>○ Robin Lee – SBA North Texas Exec Director</li> <li>○ Martha Lopez, Chair Hispanic family group - SBA North Texas</li> </ul> </li> </ul>
<p><b>11:00 AM – 11:45 AM</b></p>	<p><b>Caring for People with Spina Bifida over the age of 50.</b></p> <ul style="list-style-type: none"> <li>• Facilitator: Tim Brei, MD, Medical Director - Spina Bifida Association</li> <li>• Presenters:             <ul style="list-style-type: none"> <li>○ Kylie Cullinan, MD Assistant Professor - UT Southwestern, Internal Medicine / Pediatrics; Adult Developmental and Cognitive Clinic - Parkland Hospital</li> <li>○ Lisa Penn, OT (Retired), SBANT Board</li> <li>○ Jessica Voit MD, Assistant Professor, Internal Medicine, Division of Geriatric Care. UT Southwestern Medical Center</li> </ul> </li> </ul>
<p><b>11:45 AM</b></p>	<p><b>SBA Awards Presentation</b></p> <ul style="list-style-type: none"> <li>• Marie Thoming, SBA Board Chair</li> </ul>
<p><b>12:00 PM</b></p>	<p><b>Bowel Continence Across Life Span Working Group Announcement</b></p> <ul style="list-style-type: none"> <li>• David Chu, MD, MSCE, Ann &amp; Robert H. Lurie Children’s Hospital</li> </ul>
<p align="center"><b>Lunch and Networking / Visit the Exhibit Hall // 12:15 PM-1:30 PM</b></p>	
<p align="center"><b>Lunch and Learn presented by Coloplast // 12:30 PM - 1:00 PM</b> Optimizing Bladder and Bowel Care: From Clinical Insights to Product Solutions</p>	
<p align="center"><b>Walking Tours of Scottish Rite for Children (10-15 people/group) // 1:00 PM – 1:30 PM</b></p>	
<p align="center"><b>Day 1 - Breakout Sessions A 1:30 PM - 2:15 PM</b></p>	
<ol style="list-style-type: none"> <li>1. <b>Woodlawn A: Modification Mayhem:</b> Scottish Rite for Children presenters will share at-home functional and practical adaptations to support individuals with Spina Bifida.             <ul style="list-style-type: none"> <li>• Grace Evasco, OTR; Morgan Stephens, DPT; Angie Torres, APN</li> </ul> </li> <li>2. <b>Woodlawn B: Adaptive Awesomeness:</b> How to find—or start—wheelchair sports and activity programs for lifelong participation.             <ul style="list-style-type: none"> <li>• Dana Dempsey – Director, Therapeutic Recreation Dept, Scottish Rite for Children</li> </ul> </li> <li>3. <b>Reverchon A: Executive Functioning: What is it? How to Intervene? What to do if interventions are not being addressed?</b> Executive functioning is one of the key neurocognitive areas for individuals with Spina Bifida, affecting social relationships, education, and employment across the lifespan. Dr. Hammer will review its impact and offer practical guidance drawn from standardized assessments, clinical follow-up, and school-based recommendations.</li> </ol>	



**SCOTTISH RITE**

FOR CHILDREN



SPINA BIFIDA  
ASSOCIATION

**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

- Jasmine Hammer, PhD Neuropsychologist in Division of Developmental Disabilities, Scottish Rite for Children; Adjunct Assistant Professor, Psychiatry UT Southwestern
4. **Reverchon B: Building and Sustaining a Camp for Youth with Spina Bifida.** The panelists will talk about visioning and bringing a camp into existence, enhancing it over time, and sustaining it over future years.
- Facilitator: Christine Murphy, M.D., FAAP -- Scottish Rite for Children and Camp TLC
  - Panelists:
    - Robin Lee, Executive Director 0 SBA North Texas
    - Julie Carter; Program Director - Camp TLC
    - Elissa Casey, OTR, ATP - Scottish Rite for Children
5. **Auditorium: Transition and Self-management: Conversations on the Impact of Culture and Executive Function.** Transition is not an event; it is a process. As an international panel reflects on their experiences, the audience will have an opportunity to hear and share perspectives on the challenges and rewards of working through these issues in many diverse clinical and geographical contexts.
- Facilitator: Jonathan Castillo MD, University of Nebraska
  - Panelists:
    - Audrey Roach, RN-BSN, CNRN, CPN, Children's Hospital Wisconsin
    - Ann Ariksson-Schmidt, PhD, MSPH, Lund University
    - Jessica Stockman, PhD, Lund University
    - Morgan Kane, OT, Vanderbilt University
    - Heidi Castillo, MD, University of Nebraska
6. **Maple: Neuropsychology and Adult Issues / Challenges** - The presenters will share functional information from the Neuropsychology Collaborative stemming from a national scale exploration of executive function and memory issues in adults with Spina Bifida.
- Beatriz MacDonald Wer, PhD, Associate Professor, Psychiatry/Pediatrics - UT Southwestern
  - Rosalia Costello, PsyD, Assistant Professor of Medicine - University of Texas at Austin Dell Medical School



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

**Day 1 - Breakout Sessions B  
2:30 PM - 3:15 PM**

1. **Woodlawn A: Orthotics & Prosthetics: Practical Choices for Common and Complex Conditions and Strategies for Third-Party Coverage** This presentation covers how to choose among diverse orthotic support options for common and complex conditions, plus strategies for obtaining third-party payer coverage.
  - Reagan Bratten, CPO, LPO, Division of Orthotics/Prosthetics - Scottish Rite for Children
2. **Woodlawn B: Adaptive Awesomeness** (Repeat from Session A)
3. **Reverchon A: Co-Morbid Developmental Issues: Culturally Appropriate Interventions and Avoiding Barriers to Successful Services**
  - Mandy Maguire, PhD, Director of the Center for Children and Families - University of Texas
4. **Reverchon B: Building Optimal and Effective SB Clinics: Roles, Logistics & Outcomes.** Because individuals with Spina Bifida have complex medical, neurocognitive, and psychosocial needs, a strong multidisciplinary clinic structure is essential. Presenters from Scottish Rite for Children and UT Southwestern will highlight key elements of interdisciplinary care, offer guidance for clinics building or refining their programs, and facilitate shared discussion of challenges and best practices.
  - Jasmine Hammer, PhD and Shanmuga Pujitha “Puji” Jonnalagadda, MD
5. **Maple: Managing Serious Pressure Wounds in Spina Bifida: Prevention, Treatment & Follow-Up.** Wound care specialists from the Spina Bifida Program at Scottish Rite will review prevention, management, and follow-up strategies for serious wounds.
  - Cassie Calles, Certified Wound Care Nurse and Ronni Rowe, OTR, ATP
6. **Auditorium: Transition and Self-management: Conversations on the Impact of Culture and Executive Function.** (Repeat from Session A).

**Break / Visit the Exhibit Hall // 3:15 PM - 3:45 PM**

**Day 1- Breakout Sessions C  
3:45 PM - 5:00 PM**

1. **Woodlawn A: Adult Social Hour** - Informal Networking.
2. **Woodlawn B: Care Coordinators Interest Group: What is needed from SBA?** Betsy Hopson, PhD, MSHA
3. **High Tower: OT/PT Interest Group** Abbye Gieringer, OT
4. **Pickard: Clinic Care Partners Interest Group** Judy Thibadeau, BSN, MN
5. **Maple: Social Workers Interest Group** Jill Johnson, LCSW; Shannon Bevans, LCSW
6. **Reverchon A: NSBPR Interest Group** Daralyn Fulton, MS
7. **Reverchon B: Spina Bifida and Hydrocephalus Neuropsychology Research Collaborative** Jennifer Queally, PhD; Veronica Bordes Edgar, PhD
8. **Auditorium: Welcome to Our Spina Bifida Clinic World!** An opportunity for providers that are new to SB clinics to meet in a supportive environment to grow and learn. Christine Murphy, M.D., FAAP



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

**Welcome Reception / Dinner at Scottish Rite Children’s Park**  
5:30 PM – 7:00 PM

**Transportation back to the Marriott**  
7:00 PM; 7:15 PM; 7:30 PM

**SATURDAY, MAY 30, 2026**

**Addresses:**  
Marriott: 3033 Fairmount St, Dallas, TX 75201  
Scottish Rite: 2222 Welborn St, Dallas, TX 75219

**Morning Transport TO Scottish Rite**  
7:25 AM, 7:45 AM, 8:05 AM

**Breakfast / Visit the Exhibit Hall / Explore the Demonstration Posters**  
7:30 AM - 8:20 AM

**Room: Outside** of Reverchon

**PLENARY SESSIONS // 8:20 AM – 9:30 AM**

**Room:** Reverchon

<b>8:20 AM</b>	<b>Welcome Back!</b> We will begin with an update and a summary of the 5/28 Pre-Conference Workshop: Three Transition Assessment Instruments for Clinical & Research Use
----------------	---

<b>8:30 AM-9:30 AM</b>	<b>Orthopedic, Holistic, and Surgical Approaches to Spine Deformity in Spina Bifida</b> Karl Rathjen, MD, Professor, Pediatric Orthopedics, UT Southwestern; Assistant Chief of Staff Scottish Rite for Children
------------------------	---

**Break / Visit the Exhibit Hall / Explore the Demonstration Posters**  
9:30 AM - 10:00 AM

**Day 2 - Breakout Sessions D**  
**10:00 AM- 10:45 AM**

- Reverchon A: Walkers, Wheels & Mobility: Aligning Mobility Goals with Quality-of-Life**  
Panel of PT & Therapeutic Recreation specialists discuss mobility and ambulation in the context of medical, social and mental health aspects of decision-making.
  - Facilitator: Richard Adams, MD - Scottish Rite for Children



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

- Scottish Rite for Children Panelists: Brenda House, PT, ATP; Karla Palacios-Reagor, MS, CTRS
- 2. **Reverchon B: Trusting the Process: Navigating Special Needs Trusts and SSI/SSDI/SSDAC** A discussion on Futures Planning with a focus on financial aspects of strategies that incorporate personal and governmental agency supports across the lifetime.
  - Barney Grossman, Vice-President, Senior Portfolio Manager - Morgan Stanley, Dallas
  - Jill Johnson, LCSW, Family Resource Center - Scottish Rite for Children
- 3. **Maple: Orthopedic, Holistic, and Surgical Approaches to Lower Extremity Issues in Myelomeningocele: Lifespan Perspectives** An extension of the earlier Plenary session with a focus on issues of the lower extremities across the lifespan.
  - Karl Rathjen, MD - Scottish Rite for Children
- 4. **Auditorium: Clinical Priorities in Neuropsychological Care for Individuals with Spina Bifida** This session will present a consensus statement developed by the Spina Bifida Association and the Spina Bifida & Hydrocephalus Neuropsychology Collaborative, highlighting key priorities to improve neuropsychological care across the lifespan.
  - Jennifer Queally, PhD - Boston Children’s
  - Veronica Bordes Edgar, PhD - UT Southwestern Medical Center
- 5. **Woodlawn A: Neurosurgery and Shared Decision Making:** This session will explore challenges in decision-making with a focus on prenatal counseling, Chiari interventions, tethered cords, the impact of SDOH on access, and realistic care plans.
  - Brad Weprin, MD. Professor and Division Chief - UTSW Pedi Neurosurgery
- 6. **Woodlawn B: Guiding Kids and Teens: Using Social Media and the Internet for Good** Overview and suggestions regarding best practices for guiding children and adolescents and their use of social media and the internet for information and games.
  - Ranjith Kasanagottu, MD, Assistant Professor Developmental Behavioral Pediatrics - UT Southwestern
- 7. **Pickard: The Bowel Management Movement: Principles and Advances in Modern Bowel Care in Spina Bifida** Updates and information from the co-authors of the Lifespan Bowel Management Protocol.
  - Maryellen Kelly, DNP - Duke University; Joy Kerr, DNP - Children's Hospital of Philadelphia; Colleen Payne, MRC - Spina Bifida Association; Eileen Sherburne, PhD - Children’s of Wisconsin

**Plenary // 11:00 AM – 12:00 PM // Room: Reverchon**

- The Transition Journey: Sexuality, Identity, and Reproductive Health from Adolescence to Young Adulthood**
- Eric Su, MD, Assistant Professor of Adolescent Medicine - UT Southwestern Division of Developmental-Behavioral Pediatrics

**Lunch // 12:00 PM- 1:00 PM**



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

<p><b>Bowel Continence Across the Lifespan Study (BCALS) Luncheon // 12:00 – 1:00 PM</b></p> <p>David Chu, MD, MSCE, Ann &amp; Robert H. Lurie Children's Hospital of Chicago</p>	
<p><b>Opportunity for an Informal Discussion with Demonstration Poster Authors</b> 12:30 – 1:00 PM</p> <p><b>Last Chance to Visit our Vendors!</b></p>	
<p><b>PLENARY SESSIONS</b></p> <p><b>Room: Reverchon</b></p>	
<p><b>1:00 PM – 1:45 PM</b></p>	<p><b>Vocational and educational opportunities for adults with SB.</b> The Garrett Center on Transition and Disability Studies was established in 2017 to provide information, professional development, training, and resources to teachers, educators, students with disabilities, families, state agencies, and the community.</p> <ul style="list-style-type: none"> <li>Christina Gushanas, PhD, Director, Garrett Center Sam Houston State</li> </ul>
<p><b>1:45 PM - 2:30 PM</b></p>	<p><b>Social Skills: Achievement, Supports, and Interventions Across Childhood and Adolescence</b> Navigating life with Spina Bifida is not just about managing a physical disability. It involves complex neurodevelopmental elements including neurocognitive profiles as well as psychological and social functioning that are closely related to quality of life. These challenges can affect their social competence.</p> <p>Join the Scottish Rite for Children presenters as they explore the unique vulnerabilities and describe the layers of support and interventions crucial to success as children move into adolescence and beyond.</p> <ul style="list-style-type: none"> <li>Jasmine Hammer, PhD &amp; Shanmuga Pujitha “Puji” Jonnalagadda, MD</li> </ul>
<p><b>2:30 PM – 2:45 PM</b></p>	<p><b>Dallas Scottish Rite for Children: Successes and Challenges</b></p> <ul style="list-style-type: none"> <li>Karl Rathjen, MD &amp; Christine Murphy, MD</li> </ul>
<p><b>Hot Topics</b> <b>2:45 PM - 4:00 PM</b></p> <p>A SBCCM favorite, <i>Hot Topics</i> is back to address the most talked-about issues in Spina Bifida care.</p> <ul style="list-style-type: none"> <li><b>Endocrine Issues in MMC: GLP-1 and More</b> - Sowmya Krishnan MD, Professor, Pediatric Endocrinology, UT Southwestern Medical Center</li> <li><b>Exposure to Amniotic Fluid in the Role of Pathophysiology of MMC</b> - Patricia Santiago-Muñoz, MD, Professor, Obstetrics &amp; Gynecology UT Southwestern Medical Center</li> <li><b>Pelvic Floor Exercise Therapy for Spina Bifida</b> - Bruce Schlomer, MD, Professor, Pediatric Urology, UT Southwestern Medical Center</li> <li><b>Osteoporosis and Bone Health – Present and Future Management</b> - Mouin Seikaly, MD, Professor, Pediatric Nephrology, UT Southwestern Medical Center</li> </ul>	



**2026 Spina Bifida Clinical Care Meeting  
Futures Planning – Now**

**Closing Remarks, Appreciation, and Passing of the SBA Clinical Care Meeting Baton  
4:00 PM**

- Timothy Brei, MD, Medical Director, Spina Bifida Association
- Richard Adams, MD Division Director, Developmental Behavioral Pediatrics, UT Southwestern Medical Center; Spina Bifida Program, Scottish Rite for Children

**Evening Transport TO Marriott**

4:15 PM Transport from Scottish Rite to Marriott (Charter Up & Limo Hive)

4:30 PM Transport from Scottish Rite to Marriott (Charter Up & Limo Hive)

4:45 PM Transport from Scottish Rite to Marriott (Limo Hive ONLY)