

Spina Bifida Clinical Care Meeting
Futures Planning – Now¹
Scottish Rite for Children
May 29- May 30, 2026
Agenda

THURSDAY, MAY 28, 2026

5 PM – 7 PM	Workshop – Review of Three Transition Readiness Assessment Instruments for Clinical & Research Use Facilitators: <ul style="list-style-type: none"> ● Ellen Fremion, MD - Texas Children's ● Betsy Hopson, PhD - University of Alabama
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FRIDAY, May 29, 2026

7:30 AM - 8:30 AM	Breakfast
8:30 AM - 12:00 PM PLENARY SESSIONS	
8:30 AM - 8:35 AM	Welcome and Good Morning <ul style="list-style-type: none"> ● Tim Brei, MD, Spina Bifida Association
8:35 AM - 8:55 AM	SBA's Approach to Improving Clinical Care and the Spina Bifida Collaborative Care Network <ul style="list-style-type: none"> ● Sara Struwe, CEO, Spina Bifida Association
8:55 AM - 9:20 AM	What We Learned from the SBA Benchmark Project: Using Data to Support Future Success Among People with Spina Bifida. <ul style="list-style-type: none"> ● Kathy Sawin, PhD, CPNP-PC, FAAN, University of Wisconsin Milwaukee ● Laura Carlson PhD, MS, Spina Bifida Association ● Jonathan Routh, MD, Duke University
9:20 AM - 9:50 AM	SBA's Community Centered Research Agenda: Improving Clinical Care <ul style="list-style-type: none"> ● Laura Carlson, PhD, MS, Spina Bifida Association
9:50 AM–10:20 AM Break	
<ul style="list-style-type: none"> ● Meet our vendors and exhibitors! ● Demonstration Poster Set-Up 	

¹ **Futures planning is a person-centered process that helps a child or adult with a disability map out their vision for a good life—covering housing, finances, employment, and social connections—through coordinated support from a committed team of family, friends, and professionals.*

10:20 AM - 11:00 AM	<p>Reaching Out and Communicating With our Latino Community – Cultural and Language Considerations.</p> <p>Facilitators:</p> <ul style="list-style-type: none"> • Veronica Bordes Edgar, PhD, UT Southwestern Medical Center • Karen Dorsman, PhD - UT Southwestern Medical Center <p>Panelists:</p> <ul style="list-style-type: none"> • Robin Lee – Executive Director, SBA North Texas • Marta Lopez - Chair Hispanic Family Group, SBA North Texas • Jill Johnson, LCSW – Family Resource Center, Scottish Rite for Children
11:00 AM – 11:45 PM	<p>Caring for People with Spina Bifida Over the Age of 50</p> <p>Facilitator:</p> <ul style="list-style-type: none"> • Tim Brei, MD Facilitator <p>Panelists:</p> <ul style="list-style-type: none"> • Kylie Cullinan, MD - UT Southwestern Medical Center, Parkland Hospital. • Lisa Penn, OT (retired) - SBA North Texas Board Member • Jessica Voit, MD - UT Southwestern Medical Center.
11:45 AM - 12:15 PM	<p>Video presentation by James LeBrecht, director and producer of <i>Crip Camp (TBD)</i></p>
<p>12:15 PM - 1:30 PM</p> <ul style="list-style-type: none"> • Lunch and Networking • Meet our vendors and exhibitors! <p>1:00 – 1:30 PM</p> <p>Walking Tours of Scottish Rite for Children available, (10-15 people/group)</p>	

<p>Day 1</p> <p>Breakout Sessions A</p> <p>1:30 PM - 2:15 PM</p>	<ol style="list-style-type: none"> 1. Modification mayhem: Functional and practical adaptations you can make for the home <ul style="list-style-type: none"> • Grace Evasco, OTR; Morgan Stephens, DPT; Angie Torres, APN - Scottish Rite for Children. 2. Adaptive awesomeness: Finding and establishing wheelchair activities and programs (dance, basketball, etc.) for lifetime activity. And if you don't have anything presently, how to start your own. <ul style="list-style-type: none"> • Dana Dempsey, M.S., CTRS, Director - Therapeutic Recreation Department, Scottish Rite for Children 3. Executive functioning in children, adolescents, and young adults: What is it? How to intervene? What to do if interventions are not being addressed? Conversations with schools; practical applications drawn from validated assessments. <ul style="list-style-type: none"> • Jasmine Hammer, PhD - Scottish Rite for Children.
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	<ol style="list-style-type: none"> 4. Building and Sustaining a Camp for Youth with SB: What it takes to imagine a camp, bring it to life, nurture its growth, and ensure it thrives for years to come. <ul style="list-style-type: none"> ● Facilitator: Christine Murphy, M.D., FAAP -- Scottish Rite for Children; Camp TLC ● Panelists: Robin Lee, Executive Director, SBA North Texas; Julie Carter; Program Director, Camp TLC; Elissa Casey, OTR, ATP, Scottish Rite for Children 5. Transition and Self-Determination: 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. <ul style="list-style-type: none"> ● Facilitator: Jonathan Castillo, MD - University of Nebraska Medical Center 6. Adult Neuropsychology - Navigating Common Challenges: National insights on executive function and memory issues in adults with Spina Bifida, informed by the Neuropsychology Workgroup <ul style="list-style-type: none"> ● Beatrice Wer MacDonald, PhD, Associate Professor, Psychiatry/Pediatrics, UT Southwestern ● Rosalia Costello PsyD, Assistant Professor of Medicine, University of Texas at Austin Dell Medical School.
<p>Day 1</p> <p>Breakout Sessions B</p> <p>2:30 PM - 3:15 PM</p>	<ol style="list-style-type: none"> 1. Orthotist and Prosthetic perspectives: Decision-making regarding the wide options related to orthotic supports for common and difficult to manage conditions, and tips for getting them covered by third party payers. <ul style="list-style-type: none"> ● Reagan Bratten, CPO, LPO, Scottish Rite for Children. 2. Adaptive awesomeness (Repeat from Session A) 3. Co-morbid developmental issues: systematic early identification ,culturally appropriate interventions, avoiding barriers to successful services. <ul style="list-style-type: none"> ● Mandy Maguire, Ph - University of Texas, Dallas 4. Roles and logistics for optimal effectiveness of the inter-disciplinary SB Clinic: How to structure and design measurable outcomes. This session will focus on clinics/groups that are starting or making enhancements to their programs <ul style="list-style-type: none"> ● Jasmine Hammer, PhD - Scottish Rite for Children, UT Southwestern Medical Center ● Shanmuga Pujitha "Puji" Jonnalagadda, MD - Scottish Rite for Children, UT Southwestern Medical Center 5. Management of Pressure Wounds: Information and discussion of issues related to prevention, management, follow-up of serious wounds in individuals with Spina Bifida <ul style="list-style-type: none"> ● Cassie Calles, Certified Wound Care Nurse, Spina Bifida Program at Scottish Rite for Children ● Ronni Rowe, OTR, ATP, Spina Bifida Program at Scottish Rite for Children 6. Panel on transition and self-determination <u>(Repeat from Session A)</u>.
<p>3:15 PM - 3:45 PM</p> <p>Break</p> <p>Meet our vendors and exhibitors!</p>	

Day 1	Breakout Sessions C
3:45 PM - 5:00 PM	<ul style="list-style-type: none"> • Adult Social Hour - Informal Networking. • Care Coordinators Interest Group: What is needed from SBA? Facilitated by Betsy Hopson, PhD - University of Alabama • Therapists Interest Group Facilitator – Facilitated by Abbye Gieringer, OT - Scottish Rite for Children • Clinic Care Partners Interest Group - Facilitated by Judy Thibadeau, BSN, MN - SBA • Social Workers Interest Group - Facilitated by Jill Johnson - Scottish Rite for Children; Shannon Bevans, MSW - Arnold Palmer Orlando Health • SBA Chapter Executive Directors - Facilitated by Robin Lee, Executive Director, SBA of North Texas • NSBPR Interest Group - Facilitated by Daralyn Fulton - Scottish Rite for Children • Spina Bifida and Hydrocephalus Neuropsychology Research Collaborative - Facilitated by Jennifer Queally, PhD - Boston Children's and Veronica Bordes Edgar, PhD, UT Southwestern Medical Center • Welcome to Our Spina Bifida Clinic World* - Facilitated by Christine Murphy, M.D., FAAP -- Scottish Rite for Children (a supportive discussion for providers that are new to SB clinics)
<p>5:30 PM – 7:00 PM Welcome Reception / Dinner in the Park Scottish Rite Children's Park</p> <p>Transportation back to the hotel 7:00 PM, 7:30 PM</p>	

SATURDAY, May 30, 2026

7:30 AM - 8:30 AM	Breakfast Exhibit Hall Open – Vendors and Demonstration Posters
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8:30 AM	Welcome
8:30AM- 9:30 AM	<p>Orthopedic holistic and surgical approaches to spine deformity in Spina Bifida</p> <ul style="list-style-type: none"> • Karl Rathjen, MD - Scottish Rite for Children • Megan Johnson, MD - Scottish Rite for Children
<p>9:30-10:00 AM Break</p> <p>Meet our vendors and exhibitors!</p>	

<p>Day 2</p> <p>Breakout Session A</p> <p>10:00 AM-10:45 AM</p>	<ol style="list-style-type: none"> 1. Quality of Life; Decision-Making About Mobility - Panelists will discuss mobility and ambulation in context of medical, social and mental health aspects of decision-making <ul style="list-style-type: none"> ● Facilitated by Richard Adams, MD - Scottish Rite for Children ● Panelists will include PT/Ortho /Therapeutic Rec providers, and adolescents and young adults with Spina Bifida 2. Trusting the process - Considerations of a special needs trust and taking advantage of SSI, SSDI, SSDAC: <ul style="list-style-type: none"> ● Jill Johnson - Scottish Rite for Children ● Franck Cushner, Certified Financial Planner 3. Orthopedic, holistic and surgical approaches to lower extremity issues in myelomeningocele - An extension of the earlier Plenary session with a focus on issues of the lower extremities across the lifespan. <ul style="list-style-type: none"> ● Drs. Karl Rathjen, MD - Scottish Rite for Children ● Megan Johnson, MD - Scottish Rite for Children 4. Clinical priorities to improve the neuropsychological care of individuals with Spina Bifida: A consensus statement of the Spina Bifida Association and the Spina Bifida and Hydrocephalus Neuropsychology Collaborative <ul style="list-style-type: none"> ● Jennifer Queally, PhD - Boston Children's ● Veronica Bordes Edgar, PhD, UT Southwestern Medical Center 5. Neurosurgery and Shared Decision Making: Challenges in decision-making with focus on Prenatal counseling, Chiari Interventions, Tethered Cords, Impact of SDOH on access and realistic care plans. <ul style="list-style-type: none"> ● Brad Weprin, MD - UT Southwestern 6. Engaging the Internet for Good. Avoiding the Pitfalls Across Developmental Stages. <ul style="list-style-type: none"> ● Dr. Kasanagottu, Developmental Behavioral Pediatrics, UT Southwestern 7. Bowel management <ul style="list-style-type: none"> ● Maryellen Kelly, DNP - Duke University ● Joy Kerr, DNP - CHOP ● Colleen Payne, MRC - SBA ● Eileen Sherburne, PhD - Children's of Wisconsin-Milwaukee
<p>11:00 PM-12:00 PM</p>	<p>Sexuality / Identity / Reproductive Health in Adolescence to Young Adulthood</p> <ul style="list-style-type: none"> ● Jenny Francis, MD, MPH - UT Southwestern Medical Center ● Kwabela Blankson, MD - UT Southwestern Medical Center
<p style="text-align: center;">12:00 PM - 1:00 PM</p> <ul style="list-style-type: none"> ● Lunch ● BCAL Study Group Luncheon (open to all; pick up your lunch and join us!) ● Meet our vendors and exhibitors! <p style="text-align: center;">12:30 PM – 1:00 PM</p> <ul style="list-style-type: none"> ● Demonstration Poster Exhibit and Informal Discussion with Authors 	

1:00 PM - 4:00 PM PLENARY SESSIONS	
1:00 PM – 1:45 PM	<p>Vocational and educational opportunities for adults with Spina Bifida - panel presentation and Q&A</p> <ul style="list-style-type: none"> ● Dr. Christina Gushanas, Director, Garrett Center Sam Houston State. 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. ● TBD / Confirmation Pending ● TBD / Confirmation Pending
1:45 PM - 2:30 PM	<p>Social Skills: Achievement, Supports, and Interventions Across Childhood and Adolescence.</p> <ul style="list-style-type: none"> ● Jasmine Hammer, PhD - Scottish Rite for Children ● TBD/Confirmation pending
2:30 PM – 3:00 PM	<p>Dallas Scottish Rite for Children Successes and Challenges</p> <ul style="list-style-type: none"> ● Karl Rathjen, MD - Scottish Rite for Children ● Christine Murphy, M.D., FAAP -- Scottish Rite for Children;
3:00 PM - 4:00 PM	<p>Hot Topics</p> <ul style="list-style-type: none"> ● Endocrine issues in Myelomeningocele: GLP-1 / Precocious puberty / GH ● Osteoporosis and Bone Health ● Exposure to amniotic fluid in the role of pathophysiology of MMC ● Clinical management of vertebral anomalies in myelomeningocele ● External Stimulation (TBD)
4:00PM	<p>Closing Remarks, Appreciation, and Passing of the SBCCM Baton</p> <ul style="list-style-type: none"> ● Timothy Brei, MD, Medical Director, Spina Bifida Association; ● Richard Adams, MD Division Director, Developmental Behavioral Pediatrics, UT Southwestern Med Center; Spina Bifida Program, Scottish Rite for Children Hospital Dallas Texas