



SPINA BIFIDA
ASSOCIATION

National Efforts to Improve the Health of People Living with Spina Bifida

Spina Bifida Association of North Texas
Education Day

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Scottish Rite Frisco

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To build a better and brighter future for all those impacted by Spina Bifida

Today's Presentation

- **SBA's Focus**

- Gaps in healthcare, particularly for adults
- Experience when learning that your baby has Spina Bifida
- Building community
- Better evidence in order to make informed clinical decisions
- Community-Centered Research Agenda

- **SBA Activities – Centers for Disease Control and Prevention**

- National Spina Bifida Patient Registry, NSBPR
- Urologic Management to Preserve Initial Renal Function, UMPIRE
- Benchmark for clinic practices that result in better outcomes

Reducing Gaps in Care

Goal: People with Spina Bifida will have greater access to informed health care providers, equipment, medication, and supplies.

- Increase the number of adult providers who are knowledgeable in the care of individuals with Spina Bifida across the lifespan.
 - Funded to develop an online primary care curriculum for adult providers
 - Developing database of adult primary care and specialty physicians and physiatrists
- Advocate for reform of insurance payment policies to make equipment, medications, and supplies more affordable.
 - Transanal Irrigation
 - As a result of SBA's advocacy, TAI products will be classified as prosthetics
 - More work necessary related to pricing and coverage
 - Probably available more widely next year
- Collect and share information about providers and resources to provide effective and speedy referrals and connections for families and individuals with Spina Bifida.

SBA is Reducing Gaps in Health Care

- Training more providers to treat adults with Spina Bifida
 - Developing a curriculum for health care providers to care for adults with Spina Bifida
- Connecting more adults to providers, funded to create a database of health care providers who see adults
- Building an infrastructure for pediatric-to-adult transition-reduce that gap in care
- Advocating for improved insurance coverage of treatments, supplies, medications
- Focusing on *Guidelines for the Care of People with SB* to include more information about caring for adults
- Updating and creating Guidelines and Information Sheets

Currently underway at SBA

- **Training**

- Completed Spina Bifida 101 training for providers
- Applied for **and received** grant funding to build online on-demand training curriculum
- Host annual Clinical Care Meetings to provide practical information about best practices/networking
 - SBCCM 2025, Birmingham Alabama, June 6-7, 2025
 - Lifespan Bowel Management Protocol Workshop, June 5, 2025
 - SBCCM 2026, Dallas Scottish Rite, Date TBD

- **Connecting adults to providers**

- Clinician provider search assistance available via SBA National Resource Center
- Currently developing searchable database to launch with SBA's new website
- Identifying physiatrists who care for people with SB and who may be interested in more education about SB

Currently underway at SBA

- **Determining what clinical care models/practices are most effective**
 - More insights on best practices through CDC-funded benchmarking project
 - Pursuing grants to study and compare outcomes of various adult clinical care models
- **Building infrastructure for pediatric-to-adult care transition**
 - Launched multi-organization coalition to advance a federal transition policy
 - Hosted successful congressional briefing on transition that generated significant interest
 - Professional Advisory Council Committee surveying SB clinics to learn transition preparation and execution practices and barriers

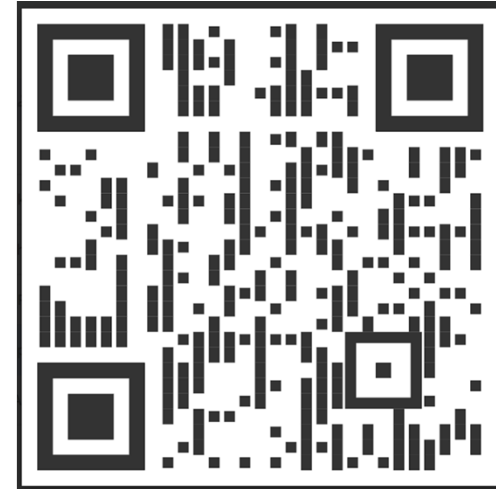
Currently underway at SBA



- **Improving insurance coverage of treatment, supplies, medications**
 - Increased number of catheter billing codes and separate coding for hydrophilic catheters
 - Successfully advocated CMS to classify transanal irrigation systems as prosthetics; financial advocacy to follow
 - Developing legislation to create pilot program to provide insurance coverage of orthotics to reduce skin breakdown on feet, infections, amputations

Currently underway at SBA

- **Standardizing adult Spina Bifida care**
 - Continued updates to and distribution of *Guidelines for the Care of People with Spina Bifida*
 - <https://www.spinabifidaassociation.org/guidelines/>
 - SBA Clinic Care Partners (30) have renewed their partner status 2025-2030 which includes the addition of two new standards.
- **Informing people with Spina Bifida and care partners**
 - Replaced four yearly, in-person Education Days with monthly virtual education series that expands reach and viewership

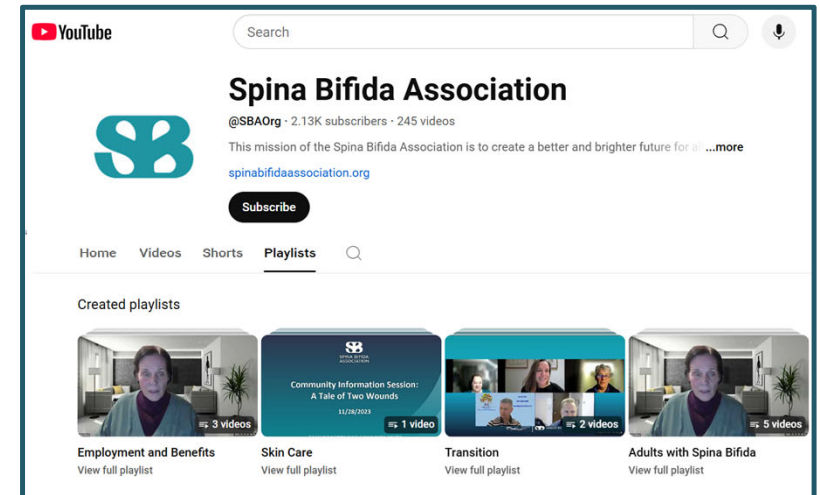


2024 Programming Highlights



Snapshot

- Live, virtual educational sessions: 17
- Recorded-only presentation: 1
- *New Voices for Spina Bifida* sponsored presentations: 3
- Number of Different Presenters: 29
- Registrants: 3,638
- Donations: \$2,849.79
- Recording Views (YouTube) as of 12-10-2024: 3,944



Diagnosis to Birth + Three Months

Goal: Improve the Diagnosis and Pregnancy Experience

- Improve the way the diagnosis of Spina Bifida is delivered to parents in order to reduce maternal/family stress and ensure that parents have accurate information about all the options available.
- Connect all newborns and their families with Spina Bifida to qualified clinical care.

Currently underway at SBA

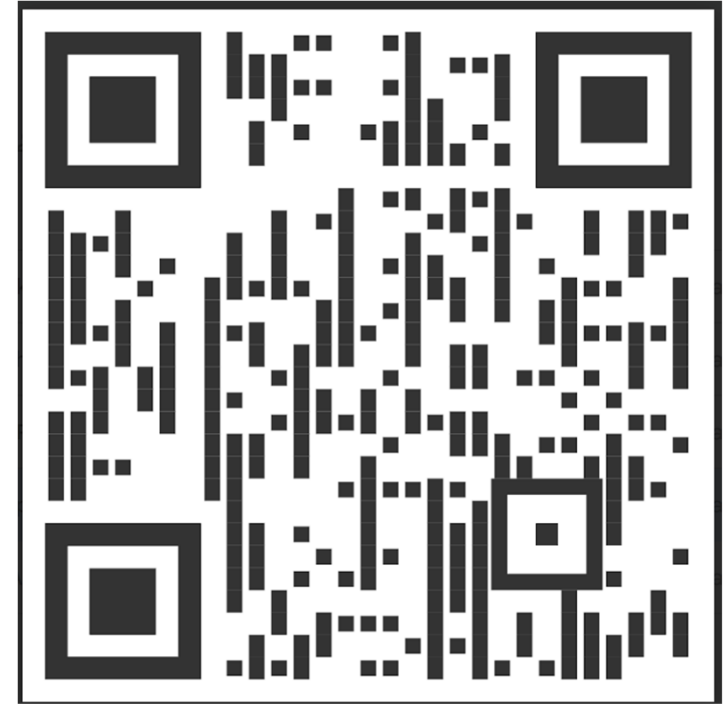
Collaborated with partners to develop two new tools

- **Care plan for new and expectant parents**
 - *A Guide to Spina Bifida for Expectant and New Parents*
 - *My Baby with Spina Bifida*, under development
 - Plan of Care documents, under development
 - Prenatal Closure, open and closed
 - Postnatal closure
 - Adoption and Termination
 - NICU
 - First 3 Months

- ***Understanding the Spina Bifida Diagnosis.***
<https://www.spinabifidaassociation.org/blog/understanding-a-spina-bifida-diagnosis/>

Available Now at SBA

- **Expectant Parent Peer Support Group**
 - Developed and growing a peer-support network for expectant parents
 - Training curriculum developed for new parent partners
 - Newly expecting parents can request a trained mentor to support and guide as needed

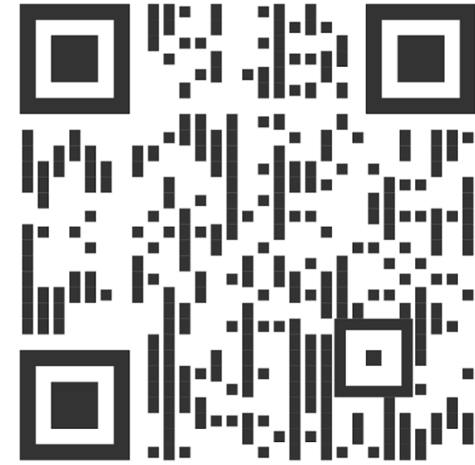


<https://www.spinabifidaassociation.org/expectant-parents/>

Building Better Evidence

Goal: The Spina Bifida community will have access to higher quality, more comprehensive, community-centered research and data

- Expand data gathering efforts to supplement the CDC National Spina Bifida Patient Registry and support additional research.
- Facilitate sharing and dissemination of research at conferences, in online resources, and with other outreach activities.
- Generate funded research that advances the **SBA Community-Centered Research Agenda**.



Happening Now

- **Groups advance research opportunities around the Community-Centered Research agenda**
 1. Bowel Incontinence
 2. Mental Health
 3. Self-Management
 4. Transition
 5. Urinary Incontinence
 6. Weight Management and Related Issues
- **Share learnings and generate interest in research through World Congress and Clinical Care Meetings**
- **Advocate for additional funding for the National Spina Bifida Patient Registry (NSBPR) to include more clinics and expand data collected**
- **Develop patient-reported outcomes registry to supplement NSBPR data**

Spina Bifida Community-Centered Research Agenda (SBC CRA)

Research Agenda Activities Prioritize

- **Bowel Incontinence**

- Longitudinal analysis of individuals in the NSBPR who achieve bowel continence in childhood and maintain it in adulthood.
- Retrospective review of surgical variation of bowel procedures amongst clinics in the NSBPR.
- Survey of Adults and Bowel Management Protocols – online survey with over 100 responses.
- Study on Bowel Boot Camps outcomes

- **Transition**

- Commentary paper on gaps in literature:
 - ways medical professionals can help parents support their children to become adults
 - ways health care workers can support transitioning adolescents to adult services.

Research Agenda Activities Prioritize

- **Self-Management**

- Survey of adults with SB – focuses on demographic data, condition variables, ability to self-manage medical needs, employment status, social relationships, living arrangement
- **Community-based study exploring facilitators and barriers to self-management skills**

- **Weight Management and Weight Related Issues**

- **HCP's Beliefs and Attitudes Surrounding Obesity** – paper sharing the results of this survey is underway.
- Being developed: Survey of adults with Spina Bifida on expectations and experiences surrounding weight management

Research Agenda Activities Prioritize

- **Urinary Incontinence**
 - **Data Analysis underway “Association between Distance to SB Clinic and Urinary and Renal Outcomes among SB Patients enrolled in the NSBPR.”**
 - Collaborative project with Bowel Incontinence workgroup, DAP looking at long term outcomes of continence programs.
- **Mental Health**
 - **Feasibility to use the PROMIS Mental Health Measure (depression and anxiety) in Spina Bifida Clinics: Children's Hospital Colorado; Lurie Children's Hospital; Nationwide Children's Hospital; Kennedy-Krieger Institute**
 - Each gathers mental health data from pediatric and adult patients using the PROMIS anxiety and depression questionnaires

Spina Bifida Activities at the Centers for Disease Control and Prevention (CDC)

Goals of CDC Activities

- **Collect and use data to provide information about the spina bifida population across the lifespan**
 - Survival/Mortality
 - Health Outcomes
 - Transition
 - Interventions
 - Ageing
- **Through SBA, implement activities that improve health outcomes for individuals with Spina Bifida across the lifespan**

Some CDC Activities

- **National Spina Bifida Patient Registry (NSBPR), 2008**
- **Skin Breakdown Prevention Bundle, 2016**
- Quality of Life Pilot (NSBPR), 2019
- Transition from Pediatrics to Adult Care, American Academy of Pediatrics, 2019
- **Urologic Management to Preserve Initial Renal Function for Young Children with SB, (UMPIRE), 2014**
- **Identification of Best Practices in SB Clinics**
- Estimate the Prevalence of SB in the US, 2022

National Spina Bifida Patient Registry

- **SBA advocated Congress for the creation of a Registry (NSBPR)**
 - Began enrolling in 2009
 - To improve the care of people living with SB
 - Data from SB clinics that are funded by CDC to collect clinical and demographic data from patients/families who consent to participate
- **More than 12,000 people (0-89 years) have contributed data to the Registry**
 - 65% 5-21 years
 - 52% female
 - 76% myelomeningocele

National Spina Bifida Patient Registry

- **What we have learned**

- 69 /100 participants lack bladder control
- 53/100 participants lack bowel control
- 29/100 participants have experienced issues with skin health
- 29/100 participants exclusively use a wheelchair

Urologic Management to Preserve Initial Renal Function for Young Children (UMPIRE)

- **Began enrolling in 2015**
- **Funded clinics (9) have collaborated with CDC**
 - Maintain initial bladder and kidney health for children with myelomeningocele
 - Determine the appropriate bladder and kidney evaluation schedule and treatment steps, birth to 10 years
- **Most babies have healthy kidneys and are at higher risk of:**
 - Urinary tract infections
 - Scarring of the kidneys
 - Loss of kidney function

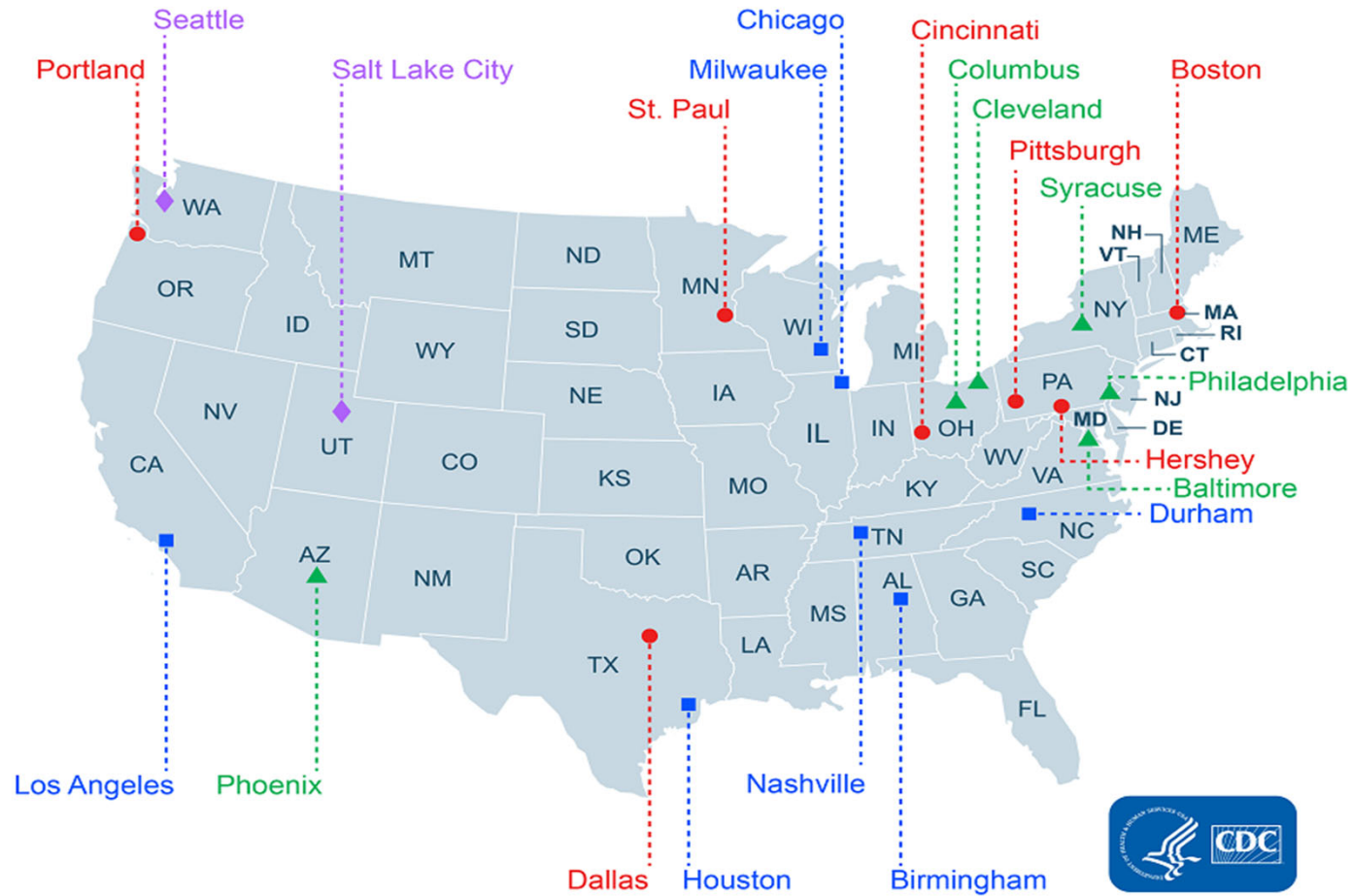
UMPIRE

- **Enrolled to date: 636 infants**
- **Most babies born with myelomeningocele have normal kidneys at birth**
- **Prophylactic antibiotics given routinely to prevent UTIs may not be necessary**

Spina Bifida Clinics in NSBPR and UMPIRE



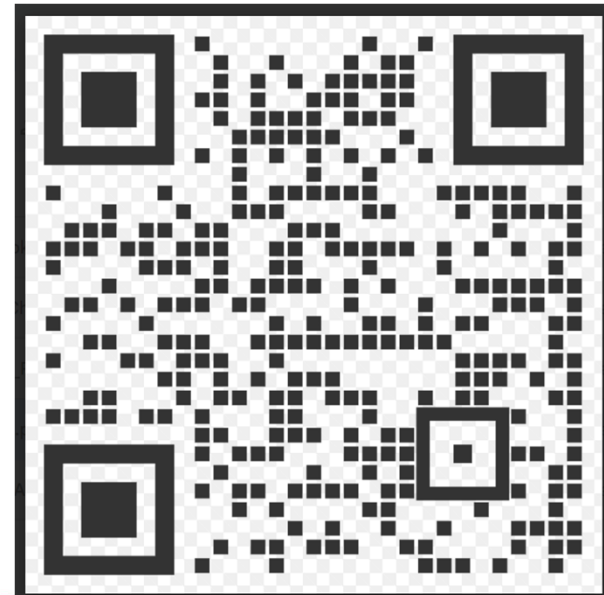
- **NSBPR**
- **UMPIRE**
- **Both NSBPR & UMPIRE**
- **NSBPR (non-funded)**



Skin Breakdown Prevention Bundle

- **“Did You Look?” developed in 2016 by CDC staff, SBA, SB clinicians**
 - Health education for providers, patients and families
 - Skin assessment
 - Risk for breakdown assessment
 - English and Spanish
- **NSBPR collects skin breakdown occurrences**

<https://www.spinabifidaassociation.org/resource/did-you-look-skin-integrity-bundle/>



Benchmarking to Identify Best Clinical Practices



- **SBA is working to identify and define systems, practices and attitudes that influence outcomes in Spina Bifida Clinics**
 - bowel and bladder continence
 - mobility
 - skin breakdown
- **Aim:**
 - Identify system-level factors that can contribute to improved health outcomes; share that information broadly so more clinics have the option to adopt and implement these attributes.

Summary of Activities at SBA and CDC

- **SBA advocates for opportunities to improve the care and lives of people living with Spina Bifida**
 - Evidence
 - Affordable access to needed supplies and treatments: orthotics, transanal irrigation, catheters
- **SBA provides education, support, connections for people living with SB and their care partners**
- **SBA connects with the SB clinical community to advocate for care standards that matter**
- **CDC responds to the advocacy efforts of SBA with needed programs**
 - NSBPR
 - UMPIRE
 - Quality of Life
 - Population estimate
 - Others

Questions?

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