SBA Mission & Core Programs
The mission of the Spina Bifida Association is to promote the prevention of Spina Bifida and enhance the lives of all affected.

We work to make a practical, positive difference every day, helping to improve care so individuals can enjoy life to the fullest.

We provide information, resources, assistance, advocacy, and connections to help all those affected by Spina Bifida.
SBA Core Programs

- Research
- Clinical Care
- Advocacy
- Education & Support
- Network Building
RESEARCH

SBA, through the Spina Bifida Collaborative Care Network, leads research to enhance the quality of life for people with Spina Bifida.
Research

Conduct Research

Facilitate Research

Create Research Agenda
Conduct Research

- Adult Survey
- Community Survey
- AFOs
- DME Coverage
Facilitate Research

Registry for women with disabilities interested in participating in gynecological and reproductive health research (University of MI)

Patient care perspective on the catheter-using experience and the decision-making process to buy catheters (Northwestern University)

Neonates with Myelomeningocele and Sleep-Disordered Breathing (University of MI)

Body Composition and Energy Expenditure in Youth with Spina Bifida (University of WI Milwaukee)

Survey to learn more about patient and caregiver experiences managing congenital urologic conditions (UCSF)

Sexual health education for people with Spina Bifida and Cerebral Palsy (University of WI Madison)
Research Agenda

HEALTHCARE GUIDELINES RESEARCH GAPS

• Publish Guidelines - research gaps identified
• Publish community- research priorities identified

RESEARCH PRIORITIES OF PEOPLE LIVING WITH SPINA BIFIDA
• Use community’s research priorities to advocate for funding (NIH, PCORI, etc.) and to identify Calls for Proposal that investigators can pursue

RESEARCH THAT CAN BE DONE WITH NSBPR
• Review community priorities and opportunities for research in NSBPR
• Review Guidelines and opportunities for research in NSBPR

HIGH PRIORITY RESEARCH

Patient-oriented non-registry research

Non-patient-oriented registry research

Patient-oriented registry research
SBA spearheads, through the Spina Bifida Collaborative Care Network, efforts to improve clinical care for all people with Spina Bifida.
Clinical Care Approach

- Clinics/HCPs
- Translational Research
- Partnerships
- Adult Care
- Outcomes
- Transition
Clinics/HCPS

present the

Spina Bifida Clinical Care Meeting
GUIDELINES FOR THE CARE OF PEOPLE WITH SPINA BIFIDA
Outcomes

PROs

Results

About the National Spina Bifida Patient Registry

CDC programs and research improve the quality of life and encourage full participation at every age for those with spina bifida. In 2006, a survey of spina bifida clinics across the United States conducted by the Spina Bifida Association (SBA) identified differences in staffing, delivery of services, and patient care. To address these gaps, SBA’s Professional Advisory Council advocated for the establishment of the National Spina Bifida Patient Registry (NSBPR) at CDC, to collect the scientific data needed to evaluate existing medical services for spina bifida patients. Established in 2008, the Registry provides the framework for a systematic approach to improving the quality of care received at spina bifida clinics nationwide.

The CDC funds and manages the NSBPR. Progress toward project milestones is monitored, and experts are consulted to ensure the scientific data are usable and valuable to researchers, health care professionals, and families affected by spina bifida.

Findings from the National Spina Bifida Patient Registry

The Centers for Disease Control and Prevention (CDC) reports findings from the National Spina Bifida Patient Registry. The Registry collects information from patients to better understand the associations between medical procedures and health outcomes.
Transition Support
Partnerships

American Urological Association

American Academy of Pediatrics

Association of Academic Physiatrists
ADVOCACY

SBA advocates for positive change to the issues impacting the lives of people with Spina Bifida.
Strategies for Advocacy

- Appropriations
- Grassroots
- Coalitions
- Teal on the Hill
- State
2019 Advocacy Priorities

NSBP

$2 million increase for CDC National Spina Bifida Program including the National Spina Bifida Patient Registry
Appropriations

- NSBP
- NSBPR
- SBCCN
- UMPIRE
CDC Funding Increase Will Aid

Increase clinic participation in NSBPR

Research Barriers to Adult Care
Social Determinants of Health
Hydrocephalus Protocol
Sudden Unexplained Death
# of People with SB
Be Part of Teal on the Hill from Anywhere!

Our second annual Teal on the Hill advocacy day has nearly 125 people attending. We’re looking forward to meeting with members of Congress to make connections, advocate for people with Spina Bifida, and tell our stories.

We know not everyone is able to travel to advocate, but you can join in from wherever you are by participating in SBA’s 2019 virtual Teal on the Hill.

Join SBA’s 2019 virtual Teal on the Hill from any tablet, smartphone or computer and contact your Members of Congress with a few clicks of a button. Messages have been created for you to send via email, Facebook, and Twitter. You can tailor the message to share your story and focus on issues important to you.
Coalitions

- Support other disability legislation
- Support select corporation legislation
- Support other health related legislation
2019 Advocacy Priorities

Protect access for specialized equipment for manual wheelchairs by supporting the House and Senate bills (HR 3730 and S 486 respectively)
EDUCATION & SUPPORT

SBA Empowers members of the Spina Bifida community with information and support to improve their quality of life.
Education and Support

Information & Support

Education

NRC
SBM’s National Information and Support Center (NISC) is the only service in the United States exclusively dedicated to addressing your questions about living with Spina Bifida. Whether you have Spina Bifida; recently learned that you are expecting a child with Spina Bifida; are a parent, family member, caregiver or other loved one of a person with Spina Bifida; or provide care or community services to people with Spina Bifida, the NISC can help you:

- Find the closest SB Chapter or support community
- Identify the nearest Spina Bifida clinic or center of care
- Find local support agencies and services
- Submit complex health-related questions to specialists in Spina Bifida care
- Find information to address learning and health challenges in the school environment
- Identify health fact sheets
- ...And more!
NETWORK BUILDING

SBA serves as a hub to connect Chapters, clinics, and the broader community to improve the quality of life of people affected by Spina Bifida.
Network Building

Strengthen SBA Chapters

Strengthen awareness and understanding of SBA activities and resources for all audiences
Communications

UPDATE
WE TURNED THE HILL TEAL

On May 9, 2019, over 200 Spina Bifida advocates came together on Capitol Hill, holding over 75 meetings with Members of Congress for the Spina Bifida Association’s 2nd annual advocacy day, Turn the Hill.

Our force advocates asked their members to fund an increase of $2 million for the National Spina Bifida Program (NSBP) at the Centers for Disease Control and Prevention (CDC), protect access for specialized equipment for manual wheelchairs by supporting the House and Senate bills HR 3750 and S 488 respectively, and sign on to the Spina Bifida Caucus.

And, at the end of the day, we received word that our request for $2 million for the NSBP at the CDC had been approved by the House Appropriations Committee. The work continues as it moves to the Senate.

Mark Your Calendars

The 2020 Hill will be held Sunday, April 25 - Tuesday, April 27. We’ll be returning to the same hotel, Arbor Inn Nowhere, as last year.

Join SBM’s Virtual Hill on the Hill

You can advocate from anywhere using your smartphone, tablet, or computer. We’ve created messages for our three magic “sets” and with a few clicks, you can send messages via email and Twitter. Please consider sending messages for all three sets.” Take action here.

Danna Jones testifies before the House Committee on Labor Health and Human Services

Thank you, Danna, an adult from California, testimony.

Tea on the Hill Scholarship Recipient Diane Goss - In Her Own Words

Diane Goss, an adult with Spina Bifida from Iowa, was a member of “Tom’s Team”, a scholarship recipient from Tom Sizemore Memorial Scholarship, which was generously donated by the family in memory of Tom, an adult with Spina Bifida who passed away in November 2016. Scholarships were also awarded to Kristen and Emily, who also had Spina Bifida.
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THANK YOU