



SPINA BIFIDA
ASSOCIATION

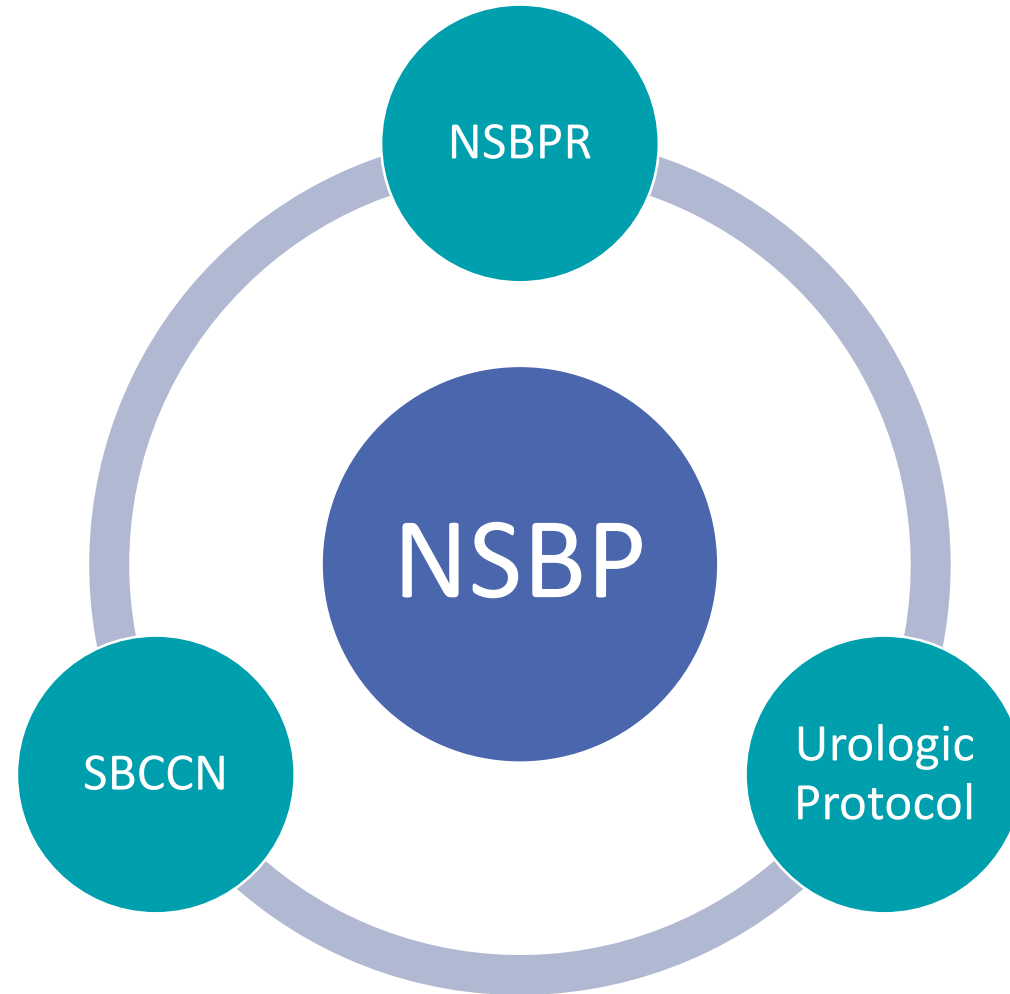
SBA Advocacy and SBCCN

Sara Struwe

President & CEO

Spina Bifida Association

Funding at CDC



CDC Funding

- Research on sudden unexplained death in the SB Community
- Determine # of people with SB
- Increase clinic participation in NSBPR
- Develop studies on social determinants of health
- Create Hydrocephalus Protocol
- Research Barriers to transition to adult care and analyze models of adult care

Spina Bifida Collaborative Care Network

Identify & facilitate the provision of expert clinical care & necessary educational resources

Monitor, track, and evaluate the care in SB clinics

To Improve the health of people with SB

Identify research priorities

Advocate for the best practices as they are identified (Guidelines)

Spina Bifida Collaborative Care Network

Identify the needs of people with SB

- Collaborate with SB clinics/SBA Chapters
- Clinical care monitoring & tracking
- National Resource Center & Surveys

Connect & communicate with Adults With SB

- Info on health status
- Barriers to health care
- Adult survey

Identify ways to meet these needs

- Collaborate with SBA Chapters/SB clinics

Spina Bifida Collaborative Care Network

People with SB will have access to knowledgeable, experienced healthcare professionals who are connected to SBA, and:

- * Enhance relationships with HCPs
- * Connect people with SB with others, needed info, and resources
- * Connect HCPs to established care network
- * Increase access to SB care via expanded network
- * Establish collaboration among HCPs, Chapters, and SBA



SBA Response to CDC Funding Announcement

2019-2024

Purpose of the Funding

Expand the work of the Spina Bifida Collaborative Care Network (SBCCN) to identify and encourage rapid adoption of best practices based on available evidence for care for persons with SB.

Communication

Clinic/Provider
database
maintain

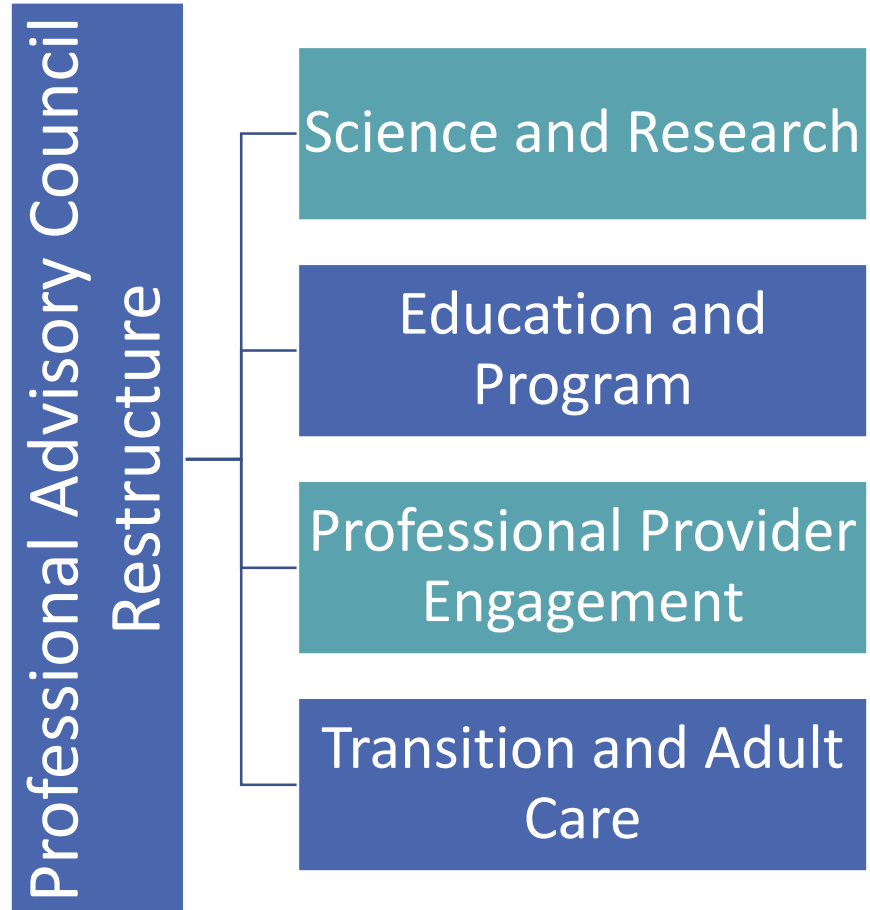
HCPs

SBA Chapters

Families,
caregivers,
adults

Programs
(NRC, SB
Connect)

Promote/Disseminate Health Care Guidance



Promote/Disseminate Health Care Guidance



Promote/Disseminate Health Care Guidance

Meetings About SB Care

- SB Clinical Care, June 28-20, 2019 (www.sbclinicalcaremeeting.org)
- 2019 Education Days (San Francisco, Houston, Las Vegas, Memphis)
- World Congress 2022

Share information and research via

- Network
- List serv

**HEALTHCARE GUIDELINES
RESEARCH GAPS**

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

Patient-oriented non-registry research

Non-patient-oriented registry research

**HIGH
PRIORITY
RESEARCH**

Patient-oriented registry research

**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

Attributes of SB Clinics with Best Outcomes

Identify using NSBPR data	Visit identified clinics	Share what is learned with other clinics
<ul style="list-style-type: none">• Bowel continence• Bladder continence• Skin breakdown• Mobility	<ul style="list-style-type: none">• Practices• Patterns• Attitudes	<ul style="list-style-type: none">• Over 100 clinics

SBA Clinic Care Partner Characteristics

Attributes & practices important to the care of people with SB

- Care coordination
- Transition
- Family advisory committee

Present opportunity at Clinical Care Meeting (June 2019)

- Clinics apply for consideration
- Partner designation indicated on SBA website

Influence Adult Care

Educate

Adults

Health Care
Providers

Listen

Adult
Survey

NRC

Advocate

AAP Project

T2C

SB Community Role in SBCCN

1	Share Guidelines (download app!) with physicians and hospital staff
2	Respond to survey about research gaps
3	Reach out to NRC with hard to solve issues

Health Care Professionals Role in SBCCN

1	Become an SBA Clinic Partner
2	Become and SBA Clinical Care Partner
3	Use Guidelines & download the app
4	Attend SB Clinical Care Meeting, World Congress on the Care and Research of SB
5	Join the Health Care Professionals Listserv
6	Support Chapter activities
7	Participate in Teal on the Hill
8	Support SB Awareness Month activities
9	Speak at SBA Education Days

Chapter Role in SBCCN

1	Share information about SBA and SBCCN to your constituents
2	Share information about the Guidelines with your constituents
3	Share information with SBA about issues and local HCPs/Clinics
4	Participate with SB Clinics on education



Guidelines for the Care of People with Spina Bifida

An Overview

Guidelines Development History

Guidelines for SB Health Care Services throughout the Lifespan

- 1990

Revision

- 1995
- 2006

Guidelines for the Care of People with SB (2018)

- Includes more evidence
- Expanded number of topics important to people with SB
- Transparent methodology

Goals/Assumptions

Newborn to Adult

Appropriate for
PCPs

Topics Important
to SB Community

Include Important
Adult Topics

Transparent &
systemic
processes

Accounts for
situations without
evidence yet

Goals/Assumptions

Consensus building methodology adds value



Use other examples like Muscular Dystrophy



Strengthen recommendations through formalized techniques



Expose gaps in knowledge

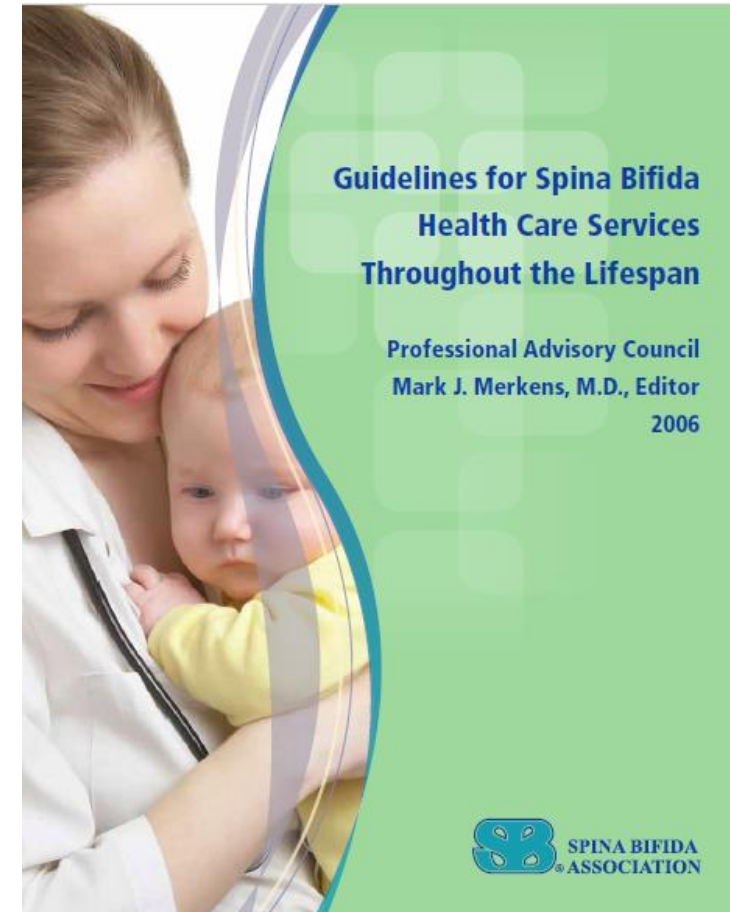


Introduce debate on uncertain topics

Previous Guidelines

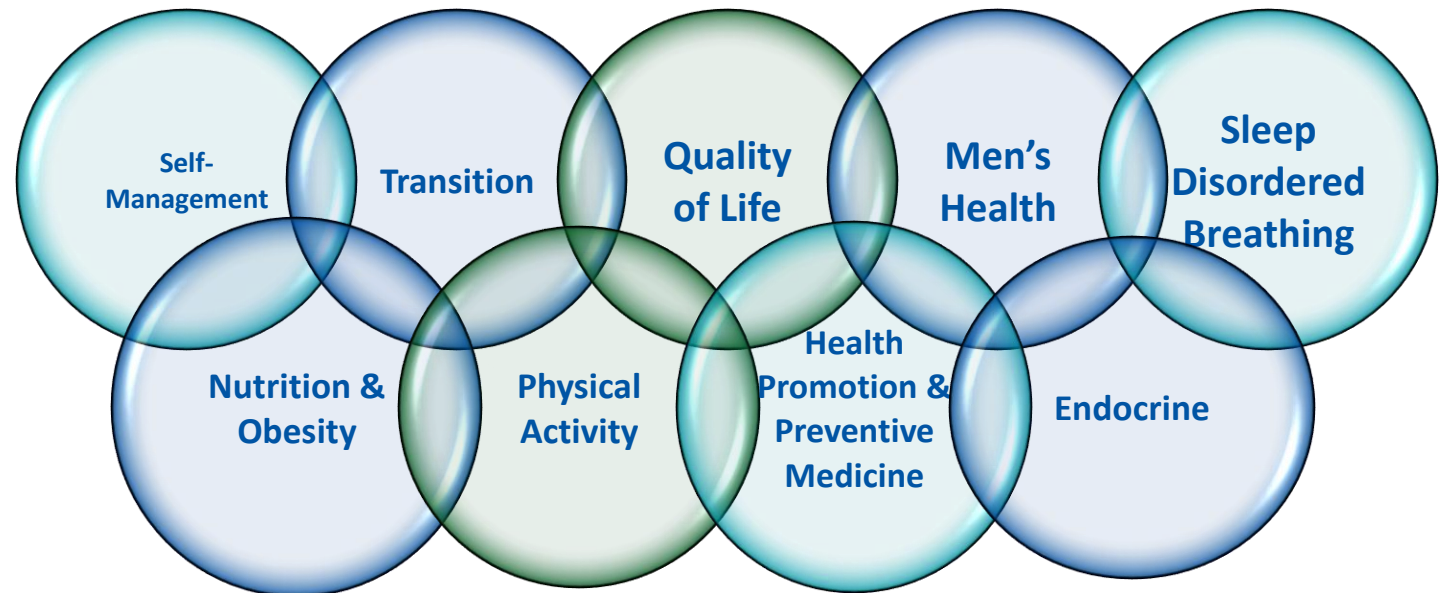
3rd Edition in 2006

14 Topics



Guidelines for the Care of People with SB

- 2014 -- SBA and CDC convened steering committee
- Concluded an update needed
- Some prior topics merged, separated, renamed
- 9 new topic areas suggested:



Oversight

- Medical Director
 - Tim Brei, MD
 - Steering Committee Co-Chairs
 - Pat Beierwaltes,
 - Brad Dicianno, MD
 - Nienke Dosa, MD
 - Patient Advisory Panel
 - 6 Expert Reviewers
- SBA Executive Committee
 - Sara Struwe
 - Lisa Raman
 - Jerome Chelliah
 - Juanita Palener
 - Sheliah Roy
 - 24 Working Groups
 - Working Group members and Chairs
 - CDC Staff Consultants
 - Judy Thibadeau
 - Julie Bolen
 - Adrienne Herron

Methodology

```
graph TD; A[ICF Framework] --> B[Clinical Questions vetted by SB Community]; B --> C[Recognized consensus-building methodology]; C --> D[Expert Review];
```

ICF Framework

Clinical Questions vetted by SB Community

Recognized consensus-building methodology

Expert Review

Literature Review

Databases

Medline
PubMed
Web of Science

Cochrane Library
CDC Library
PyschInfo
JSTOR

Google Scholar
ProQuest
INAHL

Inclusion/Exclusion Criteria

Inclusion Criteria	Exclusion Criteria	Additional inclusion/Exclusion Criteria for Each Section
<ul style="list-style-type: none">• Publication year 2002 to 2015• English language• Peer-reviewed at least one of these key terms:<ul style="list-style-type: none">• Myelomeningocele,• Lipomyelomeningocele,• Meningocele,• Neural tube defects,• Spinal dysraphism,• Spina bifida	<ul style="list-style-type: none">• theses, dissertations, abstracts without full text, conference presentations, newsletters, anecdotal papers• animal studies	<ul style="list-style-type: none">• Determined by each workgroup

Levels of Review

1

- Read titles and abstracts to determine if the article appeared to address inclusion criteria

2

- Read full manuscript to confirm that the article addressed inclusion criteria

Lit Review



- Level 1: 2449 Abstracts
- Level 2: 874 full manuscripts

Participants



- Over 100 volunteers
- 6 adults with SB
- 4 parents of children with SB

2006 & 2018 Guidelines Sections & Working Groups

Table 2: 2006 and 2018 Guidelines Sections and Working Groups		
2006 Guidelines Sections	2018 Working Groups	2018 Guidelines Sections
Prenatal Counseling	Prenatal counseling	Prenatal counseling
Care Coordination	Care coordination	Care coordination
Psychosocial Development	Mental Health	Mental Health
Learning And Education	Neuropsychology	Neuropsychology
Family	Family Functioning	Family Functioning
Sexual Development & Function	Sexual Health & Education	Sexual Health & Education
Independence	Independent Living	Self-management & Independent Living
	Self-management	
Latex Allergy	Latex	Latex
Integument	Integument (Skin)	Integument (Skin)
Bowel Function And Care	Bowel Function And Care	Bowel Function And Care
Urology	Urology	Urology
Orthopedics & Mobility	Orthopedics	Orthopedics
Neurosurgery - Hydrocephalus	Neurosurgery	Neurosurgery
Neurosurgery - Chiari II Malformation		
Neurosurgery - Syringomyelia		
Neurosurgery - Tethered Spinal Cord		
Women's Health	Women's health	Women's health

2006 & 2018 Guidelines Sections & Working Groups

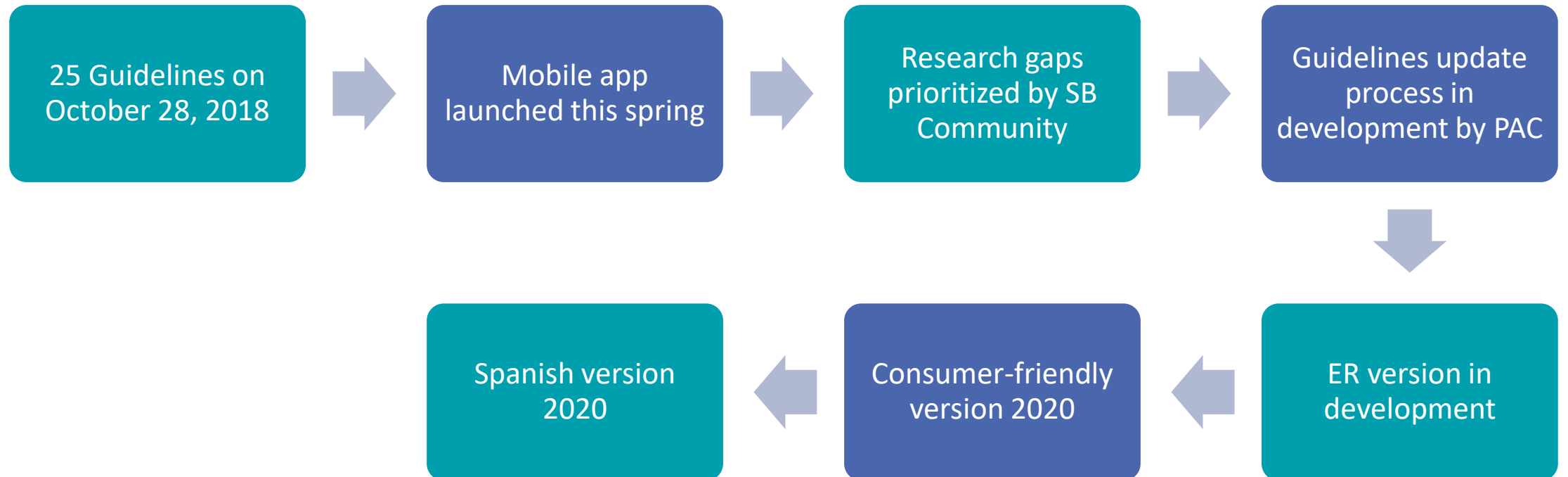
	Men's health	Men's health
	Sleep-related Breathing Disorders	Sleep-related Breathing Disorders
	Quality of life	Quality of life
	Physical activity	Physical activity
	Transition	Transition
	Health Promotion & Preventive Medicine	Health Promotion & Preventive Medicine
	Endocrine - Short stature	Endocrine - Short stature
	Endocrine - Precocious Puberty	Endocrine - Precocious Puberty
	Endocrine - Metabolic Syndrome	Nutrition, Metabolic Syndrome & Obesity
	Nutrition & Obesity	



Format of New Guidelines Document

Outcomes:	What we wish to achieve with good care
Clinical Questions:	Important questions that were targets of the lit review
Guidelines:	Recommendations for care that are based on the lit review and clinical consensus
Research Gaps:	Important topics with out research or consensus

Status of Guidelines Project



Guidelines for the Care of People with SB

- Neuropsychology and Neurosurgery
 - Neuropsychology
 - Neurosurgery
- Mobility, Orthopedics, and Physical Activity
 - Mobility
 - Orthopedics
 - Physical Activity

Guidelines for the Care of People with SB

- Urology and Sexual Health
 - Men's Health
 - Sexual Health
 - Urology
 - Women's Health

Guidelines for the Care of People with SB

- Specific Health Care Issues
 - Bowel Function and Care
 - Endocrine: Puberty & Precocious Puberty
 - Endocrine and the Use of Human Growth Hormone
 - Integument (Skin)
 - Latex and Latex Allergy in SB
 - Nutrition, Metabolic Syndrome, and Obesity
 - Sleep-Related Breathing Disorder

Thank you for what
you do and for this
opportunity to share
with you why it is so
important



**SPINA BIFIDA
ASSOCIATION**