National Spina Bifida Patient Registry (NSBPR)

Sara Struwe, MPA  
President & CEO
Birth of NSBPR
Multidisciplinary Approach

- Urology
- Orthopedics
- Neurology
- Neuro-psychology
- Physical Therapy
- Nurses

Over 130 Multidisciplinary Clinics Across the US
SB Research Limitations

- Small Sample Size
- Few Randomized Controlled Studies
- Limited Studies on Long-Term Treatment Outcomes
- Insufficient Prospective Studies

Rare
Identified 2 or 3 Priorities

Identified Strategy to Create Research Network

Evidence-Based Practice in SB: Developing a Research Agenda (2003)
NSBPR Beginnings

Survey of SB Clinics

Identified Variations

NCBDDDD Funded SBA

Illuminated Gaps

SPINA BIFIDA ASSOCIATION
NSBPR Beginnings

SBA Endorse the Establishment of a SB Patient Registry

- Clinical Research
- Improve Quality of Care

Registry to Provide Infrastructure
NSBPR
Early Days
NSBPR

Congressionally Funded

Housed at CDC/NCBDDDD

Began in 2009
NSBPR Objectives

Identify → Assess → Implement

Guide & Prioritize → Compare
NSBPR Development

- Pilot
- Demo
- Deploy
- Expand

Phase 1
Phase 2
Phase 3
Phase 4
Phase 1: Pilot

- Developed a Diagnosis-Specific EMR
- Identified 20 Registry Variables
- Funded Children’s Hospitals of Alabama & Cincinnati
Phase 2: Demo

Funded 9 SB Clinics

Required 125 People with SB

Established Coordinating Committee

3 Year Period
Phase 3: Deploy

Clinics Enter Data Via EMR

Responses De-Identified & Transmitted NCBDDDD

Clinics Conduct Research on Registry Data & Patient Info

Registry Information Pooled & Distributed Back to Sites
Phase 4: Expand 2014-2019

SBCCN

Expand

14 Sites Funded

8 Sites Self-Funded
Identify & Facilitate Expert Clinical Care & Educate People with SB

Monitor, Track, and Evaluate the Care in SB

To Improve the Health of People with SB

Identify Research Priorities in SB

Advocate for the Best Care Practices in Treatment of SB
NSBPR
Today
Current Phase of NSBPR

Outcomes
2020 NSBPR MAP

https://www.cdc.gov/ncbddd/spinafida/map/sb-clinic-map.html
SUBMITTED ANNUALLY ON CHILDREN AND ADULTS

Characteristics
- Child
- Family
- Adults

Interventions
- Prenatal Closure
- Shunts

Outcomes
- Urinary Continence
- Bowel Continence
- Pressure Sores
- Mobility

Tests
- Serum Creatinine
- Urodynamics
- Sleep Study
NSBPR Demographics

Over 10,000 Participants in the NSBPR

9,545 Registry Participants at Last Visit

Birth to 80+
Non-myelomeningocele includes lipomyelomeningocele, fatty filum terminale, meningocele, split cord malformation, terminal mylecystocele.)
NSBPR Demographics

AGE BREAKDOWN

0 to < 5 years  20%
5 to < 10 years  21%
10 to < 13  12%
13 to < 18  20%
18 and older  27%
NSBPR Demographics

INSURANCE TYPE

- **Uninsured**: 1%
- **Supplementary Insurance & Public Insurance**: 3%
- **Supplementary Insurance**: 2%
- **Public Insurance**: 47%
- **Private Insurance**: 47%
NSBPR Demographics

BLADDER CONTINENCE OVERALL

- Continent: 65%
- Incontinent: 35%

Continence is defined as dry during the day in the last month.
NSBPR Demographics

BLADDER CONTINENCE BY TYPE OF SB

<table>
<thead>
<tr>
<th>Type of SB</th>
<th>Continent</th>
<th>Incontinent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myelo</td>
<td>62%</td>
<td>61%</td>
</tr>
<tr>
<td>Non-Myelo</td>
<td>39%</td>
<td>38%</td>
</tr>
</tbody>
</table>

Among Participants 5 YOA and Older
NSBPR Demographics

BOWEL CONTINENCE

- 52% Continent
- 48% Incontinent
NSBPR Demographics

BOWEL CONTINENCE BY TYPE OF SB

- **Myelo**
- **Non-myelo**

<table>
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<th>Continent</th>
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<tr>
<td></td>
<td>52%</td>
<td>73%</td>
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<table>
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<th>Incontinent</th>
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Among Participants 5 YOA and Older
NSBPR Findings

Statistics and Findings are Located at:

https://www.cdc.gov/ncbddd/spina bifida/nsbprregistryfindings.html
NSBPR Data Uses

Research

Treatment
NSBPR Research
NSBPR Committee for Science & Publication

Subgroup of Coordinating Committee

- Review Manuscripts
- Review Requests for DAPS
- PIs from Clinics, CDC Staff, & SBA
- One-Year Term Membership

Requests for DAPS
NSBPR Research by the #'s

- 7 Years
- 24 Projects
- 6 Topical Areas
NSBPR Research: Topics

General

Brain
Bladder
Bowel
Mobility
Skin
NSBPR Research: Bowel

- Bladder & Bowel Continence Among Clinics
- Surgical Management Variations in Neurogenic Bowel
- Bowel Continence in Adults with SB
- Ethnic Difference in Continence Rates
Pressure Ulcers
NSBPR Research: Mobility

- Mobility
- Neurologic Impairments & Ambulation in Adults with SB
- Ambulation Longitudinal Study
- Mobility Transfer & Wheelchair Transfer Ability
NSBPR Research: Brain

Chiari II Malformation

Hydrocephalus
### NSBPR Research: General

<table>
<thead>
<tr>
<th>Feasibility</th>
<th>Socio-demographics &amp; Outcomes</th>
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<tbody>
<tr>
<td>Participant Profiles in 10 SB Clinics</td>
<td>Status Report</td>
</tr>
<tr>
<td>Comparison of EMR &amp; Patient Reported Data</td>
<td>10 Year Review of NSBPR</td>
</tr>
<tr>
<td>Surgeries &amp; Health Outcomes</td>
<td>Philosophy of Care Delivery</td>
</tr>
</tbody>
</table>
Publications, Authors, and Summaries are Located at:

https://www.cdc.gov/ncbddd/spina bifida/nsbpr-registry-publications.html
NSBPR
Treatment
Guidelines for Spina Bifida Health Care Services Throughout the Lifespan
Guidelines Recent Revision Work

- Comprised of Medical Directors, DNP, and Physician
- Set Overall Strategy & Plans

25 Volunteer Workgroups

- Review Literature Summaries (Including NSBPR Publications)
- Revise Guidelines
- Complete Process Documents
- Vet Guidelines @ Consensus Meeting
- Receive Public Input
- Develop Final Manuscript

Steering Committee

- Publication
- Dissemination

Culmination
Guidelines

Guidelines for the Care of People with Spina Bifida

https://www.spinabifidaassociation.org/resource/guidelinespdfull/

https://www.spinabifidaassociation.org/mobile-application/
Urologic & Renal Background

**Bladder Function**
- Normal at Birth
- Dysfunctional Early

**Renal Function**
- Deterioration Begins Early
- Not Monitored Early

**In the Field**
- Diagnostic Management Similar
- No Standardized Frequency of Testing
Additional CDC/NCBDDD Research Findings

No Significant Mortality Increase for People with SB in ESRD

ESRD Younger in SB

Need to Monitor Renal Function Aggressively in Young People with SB

Panel to Address Renal Issues

Panel

Nephrology
Urology
SBA
NCBDDD
Statistician
Pediatrics
Epidemiology
Urology Nursing
NSBPR Urologic Protocol (UMPIRE)

Iterative Quality Improvement Project

Treat Prospectively Newborn to 10 YOA with SB Using Protocol

Assess Outcomes & Adjust As Needed
- Optimize Patient Outcomes
- Improve Processes
SBCCN Outcomes

Determine Attributes of NSBPR Clinics Associated with Best Patient Outcomes.

Identify NSBPR Clinics with Good Outcomes

Develop & Implement Plan to Determine Causes of Difference

Use findings to Improve Outcomes in ALL SB Clinics
SBCCN Transition & Adult Care

**Transition**
- Support NSBPR Clinics to Prepare People with SB to Transfer to Adult HCPs

**Adults**
- Conduct Follow-up Survey(s) of Adults with SB
- Develop Models of Care for Adults with SB
- Conduct HCP Training on Caring for Adults with SB
What Can You Do?
Get Involved: SBA Education & Support

Education Days
https://www.spinabifidaassociation.org/education/education-days/

WNRs
https://www.spinabifidaassociation.org/walk-n-roll-for-spina-bifida/

SB-YOU
https://www.spinabifidaassociation.org/education/sb-you/
Get Involved: SBA Clinical Care

**Attend Clinical Care Meeting**
https://www.spinabifidaassociation.org/clinical-care-meeting/

**Sign Up for List Serv**
https://www.spinabifidaassociation.org/for-health-care-professionals/sb-professionals-listserv/

**Volunteer for PAC & Committees**
Jthibadeau@sbaa.org

**Become a Clinic Care Partner**
https://www.spinabifidaassociation.org/clinics/clinic-care-partner/
Get Involved: Research

SBA PAC & Sub-Committees

Contact
Dr. Tonya Williams
tis5@cdc.gov

SB Research

SBA RAC

Contact SBA if YOU Do Research Related to SB
Get Involved: Advocacy
If You Need More Info

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