

NATIONAL SPINA BIFIDA CLINICAL REGISTRY PROJECT – Annual Visit Form

Funded by the Centers for Disease Control and Prevention
FOA# DD-08-001

Patient

Last Name _____ First Name _____

Unique ID

DEMOGRAPHICS

1. Employment

- Employed Full-time
- Employed Part-time
- Not Employed

If not Employed:

- Child or Student
- Homemaker
- Seeking work, but not currently working
- Permanently disabled

2. Marital Status

- Single
- Married
- Widowed
- Partner
- Divorced/Separated

Date of visit

Month Day Year

OUTCOMES/TREATMENTS (Since Last Visit)

3. Bladder Management

- a. Indicate method of bladder emptying. More than one may apply.
- No Management/Incontinent
 - Clean intermittent catheterization
 - Spontaneous Void
 - Vesicostomy
 - Crede
 - Indwelling catheter
 - Urostomy Bag
- b. Continent of Urine, based on the following definition "Dry, with or without interventions, during the day".

4. Bowel Management

- a. Indicate method of bowel management. More than one may apply.
- None
 - Oral Medications
 - Manual Stimulation/Disimpaction
 - Suppository
 - Irritant Enema (bisacodyl, etc.)
 - Cone Enema/Saline Enema
 - Antegrade Enema
 - Other
- b. Continent of stool based on the following definition "No involuntary stool leakage, with or without interventions, during the day".

5. Method of mobility Check only one.

- Community ambulators — These patients walk indoors and outdoors for most of their activities and may need crutches or braces or both. They use a wheel chair only for long trips out of the community.
- Household ambulators — These patients walk only indoors and with apparatus. They are able to get in and out of the chair and bed with little if any assistance. They may use the wheel chair for some indoor activities at home and school and for all activities in the community.
- Non-functional ambulators — Walking for these patients is a therapy session, in school or in the hospital. Afterward they use their wheel chairs to get from place to place and to satisfy all their needs for transportation.
- Non-ambulators — These patients are wheel-chair-bound but usually can transfer from chair to bed
- Not applicable due to age

6. Skin

Has there been a pressure sore? Yes No
If yes, indicate location. More than one may apply.

- Head/neck (back of head, ear)
- Upper extremity (shoulder, elbow)
- Lower extremity (thigh, hip, knee, shin, ankle)
- Trunk (back, chest)
- Posterior Pelvis (coccyx, sacrum, ischium)
- Perineum (penis/scrotum, vulva, groin)
- Foot (toe, heel, sole, top of foot)
- Other _____

OUTCOMES/TREATMENTS (Since Last Visit) -- Continued on Page 2 of 4

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FORM INSTRUCTIONS

Form Completion: Complete this form at the time of the patient's annual visit to the Spina Bifida (SB) clinic.

Unique ID Number: Enter the ID number generated for each patient by the SB Patient Registry Electronic Medical Record.

Date of Visit: Enter the month, day, and year the patient was seen in the SB Clinic using leading zeros before a single-digit month/day.

- 1. Employment:** Check the box that indicates the patient's current employment status. If the patient is not employed, check the box that most appropriately represents the patient's status.
- 2. Marital Status:** Check the box that represents the patient's current marital status.
- 3. Bladder Management:**
 - a. Check the box that indicates the current method of bladder emptying. If none apply, check the NO MANAGEMENT/INCONTINENT box.
 - b. Check the box if the patient is continent of urine based on the definition provided on the form.
- 4. Bowel Management:**
 - a. Check the box(es) that indicate(s) the current method(s) of bowel management. If none apply, check the NONE box.
 - b. Check this box if the patient is continent of stool based on the definition provided on the form.
- 5. Method of Mobility:** Check the box that best describes the patient's current mobility status.
- 6. Skin:** Check the YES box if the patient has had a pressure sore(s) in the last 12 months or since the last SB registry visit. If none, check the NO box. If YES, check the box(es) that describe(s) the location(s) of the pressure sore(s).

OUTCOMES/TREATMENTS (Since Last Visit)
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OUTCOMES/TREATMENTS (Since Last Visit) -- Continued from Page 1 of 4

7. Respiratory

- Check treatments that apply.
- Bi-pap; C-pap
 - Oxygen
 - Dental appliance
 - Not applicable

8. Health Insurance

- (Check all that apply)
- Straight commercial insurance
 - Commercial insurance HMO
 - Commercial insurance PPO
 - Straight Medicaid
 - Medicaid HMO
 - Straight Medicare
 - Medicare HMO
 - State High Risk Plan
 - Tricare/Other Military
 - Uninsured
 - Other: _____

9. Education

- Is patient a current student?** Yes No
If yes, check the current level of education at the time of this clinic visit.
If no, check the highest level of education achieved at the time of this clinic visit.
- Pre-elementary
 - Primary/Secondary Enter Current Grade 1-12_____
 - Technical School
 - Some College
 - College Degree Advanced Degree
 - Other, please list: _____

SURGERIES (Since last visit)

10. Neurosurgery

Yes No

a. Shunt placement (If yes, check shunt type and indicate date)

- | | | | | | |
|-----------------------------|-----------------------------|--------------------------------|----------------------|----------------------|----------------------|
| <input type="checkbox"/> VP | <input type="checkbox"/> VA | <input type="checkbox"/> Other | Date | | |
| <input type="checkbox"/> VP | <input type="checkbox"/> VA | <input type="checkbox"/> Other | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| | | | Month | Day | Year |

Shunt revision (If yes, check shunt type and indicate date)

- | | | | | | |
|-----------------------------|-----------------------------|--------------------------------|----------------------|----------------------|----------------------|
| <input type="checkbox"/> VP | <input type="checkbox"/> VA | <input type="checkbox"/> Other | Date | | |
| <input type="checkbox"/> VP | <input type="checkbox"/> VA | <input type="checkbox"/> Other | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| | | | Month | Day | Year |

Shunt removal (If yes, check shunt type and indicate date)

- | | | | | | |
|-----------------------------|-----------------------------|--------------------------------|----------------------|----------------------|----------------------|
| <input type="checkbox"/> VP | <input type="checkbox"/> VA | <input type="checkbox"/> Other | Date | | |
| <input type="checkbox"/> VP | <input type="checkbox"/> VA | <input type="checkbox"/> Other | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| | | | Month | Day | Year |

b. Shunt Infection (May be more than one)

- | | | | |
|------------------------------|----------------------|----------------------|----------------------|
| <input type="checkbox"/> EVD | Date | | |
| | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| | Month | Day | Year |

Organism

- | | Date | | |
|--|----------------------|----------------------|----------------------|
| <input type="checkbox"/> Staphylococcus aureus | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> Coagulase negative Staphylococcus | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> Escherichia Coli | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> Enterococcus species | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> Propionibacterium acnes | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> Other Gram-negative organism | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| c. <input type="checkbox"/> Chiari decompression | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| d. <input type="checkbox"/> Tethered Cord | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| e. <input type="checkbox"/> Other | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| | Month | Day | Year |

SURGERIES (Since last visit) -- Continued to Page 3 of 4

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FORM INSTRUCTIONS

- 7. Respiratory:** Check the treatments used by the patient in the previous 12 months or since the last SB registry visit. Check NOT APPLICABLE if none apply.
- 8. Health Insurance:** Check the box(es) that represent the medical care funding used by the patient.
- 9. Education:**
- a. Current student:** Check YES if the patient is currently enrolled in an educational program. Check NO if the patient is not currently enrolled in an educational program.
 - b. Current level of education or highest level achieved:** If the patient is currently a student, enter the patient's grade/level of education. If the patient is not currently a student, enter the highest education level completed by the patient at the time of the visit.
- 10. Neurosurgery:** Check the YES box if the patient has had neurosurgery in the previous 12 months or since the last SB registry visit. If none, check the NO box.
- a. Shunt Placement:** Check this box if the patient has had shunt placement surgery in the previous 12 months or since the last SB registry visit. Indicate the new shunt (s) type and the month, day, and year of insertion using leading zeros before a single-digit month/day.
 - Shunt Revision:** Check this box if the patient has had shunt revision surgery in the previous 12 months or since the last SB registry visit. Indicate the type of shunt (s) and the month, day, and year of the revision(s) using leading zeros before a single-digit month/day.
 - Shunt Removal:** Check this box if the patient has had shunt removal surgery in the previous 12 months or since the last SB registry visit. Indicate the type of shunt(s) and the month, day, and year of removal(s) using leading zeros before a single-digit month/day.
- b. Shunt Infection:** Check the EVD box if extra-ventricular drainage was used and indicate the month, day, and year the procedure was performed using leading zeros before a single-digit day/month. If an organism was identified, check the appropriate box and indicate the date of the culture result. Use leading zeros before a single-digit month/day.
 - c. Chiari Decompression:** Check this box if a Chiari decompression was performed in the last 12 months or since the last SB registry visit. Indicate the month, day and year using leading zeros before a single-digit month/day.
 - d. Tethered Cord:** Check this box if a tethered cord release was performed in the last 12 months or since the last SB registry visit. Indicate the month, day, and year using leading zeros before a single-digit month/day.
 - e. Other:** Check this box if an unlisted surgery or procedure was performed in the last 12 months or since the last SB registry visit. Indicate the month, day, and year using leading zeros before a single-digit month/day.

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SURGERIES (Since last visit) Continued from Page 2 of 4

11. Urology Surgery Yes No

Check all procedures performed and provide date.

	Date
<input type="checkbox"/> Bladder Augmentation	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	Month Day Year
Bowel Segment Used _____	
<input type="checkbox"/> Appendicovesicostomy /Mitrofanoff	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Vesicostomy	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Vesicostomy Closure	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Anti-Reflux Procedure	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Bladder Outlet Procedure	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Stone Surgery/Removal	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Orchiopexy	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Ileovesicostomy/Monti	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Other	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	Month Day Year

12. GI Surgery Yes No

Check all procedures performed and provide date.

	Date
<input type="checkbox"/> Malone Antegrade Continence Enema (MACE)	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Ileostomy	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Colostomy	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Gastrostomy tube placement	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Cecostomy button	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Other	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	Month Day Year

13. Skin Surgery Yes No

Check all procedures performed and provide date.

	Date
<input type="checkbox"/> Debridement	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Flap	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Graft	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Other	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	Month Day Year

14. ENT Surgery Yes No

Check if performed and provide date.

	Date
<input type="checkbox"/> Tonsillectomy/ Adenoidectomy	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Tracheostomy	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Other	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	Month Day Year

15. Orthopedic procedures Yes No

Check diagnoses for the procedures performed and provide the date.

	Date
<input type="checkbox"/> Scoliosis	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Kyphosis	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Hip flexion contracture	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Hip subluxation/dislocation	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Knee flexion contracture	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> External tibial torsion	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Ankle valgus deformity	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Equinus contracture	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Clubfoot deformity	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Congenital vertical talus	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Congenital Deformity of Foot	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Other	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	Month Day Year

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FORM INSTRUCTIONS

11. Urology Surgery: Check the YES box if the patient has had urology surgery in the previous 12 months or since the last SB registry visit. If none, check the NO box. Indicate the month, day and year of the surgery or surgeries performed using leading zeros before a single-digit month/day.

12. GI Surgery: Check the YES box if the patient has had GI surgery in the previous 12 months or since the last SB registry visit. If none, check the NO box. Indicate the month, day and year of the surgery or surgeries performed using leading zeros before a single-digit month/day.

13. Skin Surgery: Check the YES box if the patient has had skin surgery in the previous 12 months or since the last SB registry visit. If none, check the NO box. Indicate the month, day and year of the surgery or surgeries performed using leading zeros before a single-digit month/day.

14. ENT Surgery: Check the YES box if the patient has had ENT surgery in the previous 12 months or since the last SB registry visit. If none, check the NO box. Indicate the month, day and year of the surgery or surgeries performed using leading zeros before a single-digit month/day.

15. Orthopedic Procedures: Check the YES box if the patient has had orthopedic procedure(s) in the previous 12 months or since the last SB registry visit. If none, check the NO box. Indicate all orthopedic diagnoses for which procedures were performed and enter the month, day, and year of surgery using leading zeros before a single-digit month/day.

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MEASUREMENTS (Since last visit)

16. Weight _____kg

17. Please choose one of the following measurements:

Arm Span _____cm

Standing Height _____cm

Recumbent Length _____cm

18. Head Circumference (< 5 y.o. or first visit to the clinic):

_____cm

19. Functional Level of Lesion

9a. Check the boxes that represent the patient's right and left lowest spinal level that has reproducible movement.

	Left	Right
Thoracic (flaccid lower extremities)	_____	_____
High-Lumbar (hip flexion present)	_____	_____
Mid-Lumbar (knee extension present)	_____	_____
Low-Lumbar (foot dorsiflexion present)	_____	_____
Sacral (foot plantar flexion present)	_____	_____

REPORTS

20. Number of Spina Bifida Clinic visits in the last 12 months or since the last SB Registry visit.

- | | |
|--|--|
| <input type="checkbox"/> 0 - first visit | <input type="checkbox"/> 0 - not first visit |
| <input type="checkbox"/> 1 time | <input type="checkbox"/> 2-3 times |
| <input type="checkbox"/> 4-5 times | <input type="checkbox"/> 6 or more times |

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FORM INSTRUCTIONS

- 16. Weight:** Weigh the patient and enter the weight in kilograms (kg).
- 17. Head Circumference (< 5 y.o. or first visit to the clinic):**
Enter the head circumference of the patient in centimeters (cm).
- 18. Please choose one of the following measurements:**
- Arm Span:** Enter the distance in cm of the patient's outstretched arms, from fingertips to fingertips.
 - Standing Height:** Enter the patient's standing height in cm, if patient is able to stand upright.
 - Recumbent Length:** Enter the patient's recumbent length in cm.
- 19. Functional Level of Lesion:** Check the boxes that represent the patient's right and left lowest spinal level that has reproducible movement.
- 20. Number of SBC visits in the last 12 months or since the last SB registry visit:** Check the box that indicates the number of SBC visits made by the patient in the previous 12 months or since the last SB registry visit, not including this visit. If the patient has never been seen prior to this visit, check "0-first visit" box. If the patient has been seen before, but not in the previous 12 months, check the "0-not first visit" box.