

NATIONAL SPINA BIFIDA PATIENT REGISTRY – Initial Encounter Form

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

Patient

Last Name _____ First Name _____

Unique ID

DEMOGRAPHICS INFORMATION

1. Date of birth:

Month Day Year

2. Sex:

- Male
 Female

3. Place of birth:

State/Territory: _____

Or country: _____
(If other than USA)

4 a. Primary Race:

- White
 Black or African American
 Asian
 Native Hawaiian or other Pacific Islander
 American Indian/Alaskan Native
 Other _____
 Refused
 Unknown

b. Secondary Race:

- White
 Black or African American
 Asian
 Native Hawaiian or other Pacific Islander

- American Indian/Alaskan Native
 Other _____
 Refused
 Unknown

c. Ethnicity:

- Non-Hispanic or Latino
 Hispanic or Latino
 Refused

5. Status:

- Established Patient
 New Patient
 Transfer Patient

Date of visit

Month Day Year

SPINA BIFIDA DIAGNOSIS

6. Type of Spina Bifida (Check one)

- Lipomyelomeningocele Meningocele Myelomeningocele Fatty Filum

SURGERIES

7. Have you EVER had any of these surgeries (Check all that apply and enter date(s) if known)

- Shunt placement Malone Antegrade Continence Enema (MACE)
Shunt Functioning Yes No Ileostomy
 Chiari decompression Colostomy
 Bladder Augmentation Appendicovesicostomy/Mitrofanoff
 Ileovesicostomy/Monti Cecostomy button
 Vesicostomy

REPORTS

8. Prenatal Closure (Check one)

- Yes No

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FORM INSTRUCTIONS

Form Completion: Complete this form after the patient has consented to participate in the Spina Bifida (SB) Registry.

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

- 1. Date of birth:** Enter the month, day, and year in which the patient was born using leading zeros before a single-digit month/day.
- 2. Sex:** Check MALE or FEMALE.
- 3. Place of birth:** Enter the place of birth by U.S. state or territory or country if outside of the U.S.
- 4a. Primary Race:** Check the primary race category designated by the patient. Use the OTHER category and write in the information for racial groups not listed. Select the REFUSED category if the patient is unwilling to provide the information. Choose the UNKNOWN category if the information cannot be determined.
- b. Secondary Race:** Check the secondary race category designated by the patient. Use the OTHER category and write in the information for racial groups not listed. Select the REFUSED category if the patient is unwilling to provide the information. Choose the UNKNOWN category if the information cannot be determined.
- c. Ethnicity:** Check the ethnicity category designated by the patient. Select the REFUSED category if the patient is unwilling to provide the information.
- 5. Patient Status:** Check ESTABLISHED PATIENT if the patient has been previously seen in the SB clinic. Check NEW PATIENT if this patient has never been seen in the SB clinic before this encounter and is not a transfer from another SB clinic. Check TRANSFER PATIENT if the patient was seen in another SB clinic prior to coming to this clinic.
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.
- 6. Type of Spina Bifida:** Check the type of neural tube defect present in this patient.
- 7. Previous surgeries :** Check all surgeries that apply and enter the dates if known. If the patient has had a shunt placement, check YES if the shunt is functioning or NO if the patient currently has a shunt, but it's not functioning.
- 8. Prenatal Closure:** Check YES if patient had in-utero back closure surgery performed. Check NO if the patient did not have in-utero back closure surgery performed.