ATTACHMENT F

Medical Records Data Abstraction Form

Medical Records Data Abstraction Form

The Natural History of Spina Bifida in Children Pilot Project

MEDICAL RECORDS DATA ABSTRACTION FORM

Participant ID number (marked on each page): _____

Date information retrieved: _____ *(mm-dd-yyyy)*

Person retrieving information: _____

Name of hospital/clinic: _____

Time period covered: _____ *(mm-yyyy to mm-yyyy)*

SECTION A- NEUROSURGERY

Lesion

A1.
Date of lesion closure: _____ Information not in medical records
(mm-dd-yyyy)

A2.
Level of lesion reported: _____ Information not in medical records

---

Shunt

A3.
Hydrocephalus present?
Yes
No SKIP A4-A16
Information not in medical records

A4.
Shunt present?
Yes
No SKIP A5-A16
Information not in medical records

A5.
What date was the shunt inserted _____(mm-dd-yyyy)
Information not in medical records

A6.
What type of shunt? CHECK ALL THAT APPLY

Ventriculoatrial shunt
Ventriculo-subgaleal shunt (*this shunt is used temporarily*)
Ventriculo-peritoneal shunt
Other, *specify*_____
Information not in medical record

A7.
Has shunt revision/s been performed?
Yes
No SKIP A8-A16
Information not in medical records

Shunt Revision
Shunt Obstruction

A8.
Was the shunt obstructed?
Yes_____ (mm-dd-yyyy)
No SKIP A9-A10
Information not in medical records

A9.
Was the shunt revised?
Yes
No SKIP A10
Information not in medical records

A10.
What date was shunt reinserted_____(mm-dd-yyyy)
Information not in medical records

Shunt Infection
A11.
Was the shunt infected?
Yes_____ (mm-dd-yyyy)
No SKIP A12-A13
Information not in medical records

A12.
What was the culture result? Write type of organism
_____
_____
_____
Information not in medical records

ATTACHMENT F

Medical Records Data Abstraction Form

For office use only

A13.

Gramm Negative

Not Gramm Negative

Not enough information to determine what type of organism

Information not in medical records

A14.

Was the shunt removed and then reinserted?

Yes

No SKIP A15

Information not in medical records

A15.

What date/s removed and reinserted? _____ (mm-dd-yyyy)

A16.

Total number of shunt revisions _____

COLLECT INFORMATION FOR EACH SHUNT REVISION. IF MORE THAN ONE USE ADDITIONAL FORM (I.E., COPY OF SAME FORM)

Tethered Cord

A17.

Tethered spinal cord diagnosed?

Yes, what date _____ (mm-dd-yyyy)

No SKIP A18-A19

Information not in medical records

A18.

Surgery related to tethered cord?

Yes, *specify type of surgery and date below*

_____ Type of surgery (mm-dd-yyyy)

_____ Type of surgery (mm-dd-yyyy)

_____ Type of surgery (mm-dd-yyyy)

_____ Type of surgery (mm-dd-yyyy)

_____ Type of surgery (mm-dd-yyyy)

_____ Type of surgery (mm-dd-yyyy)

No SKIP A19

Information not in medical records

A19.

Total number of tethered cord related surgeries_____

Symptomatic Chiari II Malformation

A20.
Symptomatic Chiari II malformation diagnosed?

Yes, what date _____ (mm-dd-yyyy)
No SKIP A21-A23
Information not in medical records

A21.
Presenting symptoms of Chiari II Malformation- *check all that apply*

Difficulty feeding
Aspiration
Gagging problems
Weak cry
Arm weakness
Spacticity
High pitched cry
Temporary stridor (noisy breathing)
Apnea
Cyanosis
Other, *specify* _____
Information not in medical records

A22.
Has Chiari decompression, or any other surgery related to Chiari II malformation been performed?

Yes, *specify type of surgery and date below*

1) _____ (type of surgery)
_____ (mm-dd-yyyy)
2) _____ (type of surgery)
_____ (mm-dd-yyyy)
3) _____ (type of surgery)
_____ (mm-dd-yyyy)

No SKIP A23
Information not in medical records

A23.
Total number of Chiari II malformation related surgeries_____

Procedures Performed

A24.
MRI performed?

Yes
No SKIP A25-A28
Information not in medical records

A25.
Date of MRI _____ (mm-dd-yyyy)

A26.
MRI performed on what area?

Head/neck
Spine
Other, *specify*_____
Information not in medical records

A27.
MRI findings?

Chiari II malformation
Syrinx (syringomyelia)
Syringobulbia
Diastematomyelia
Other, *specify*_____

A28.
Total number of MRIs performed _____

COLLECT INFORMATION FOR EACH MRI. IF MORE THAN ONE USE ADDITIONAL FORM (I.E., COPY OF SAME FORM)

A29.
CT scan performed to ventricles?

Yes
No SKIP A30-A33
Information not in medical records

A30.
Date of CT scan_____ (mm-dd-yyyy)

A31.
CT scan performed on what area?

Head/neck
Spine
Other, *specify*_____

Information not in medical records

A32.
CT findings:

_____
_____
_____

A33.
Total number of CT scans performed_____

COLLECT INFORMATION FOR EACH CT SCAN. IF MORE THAN ONE USE ADDITIONAL FORM (I.E., COPY OF SAME FORM)

A34.
Notes/Comments Related to Neurosurgery:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

SECTION B - UROLOGY, BLADDER & BOWEL MANAGEMENT

B1. Level of lesion reported: _____ Information not in medical records

Bladder Anatomy & Function

B2.
What is the anatomy of the bladder?
Normal anatomy

Vesicostomy, *specify date*_____ (mm-dd-yyyy)
Other, *please specify*
_____
_____
_____
Information not in medical records

Urodynamic Assessment

B3.
Has a urodynamic study been performed?
Yes
No SKIP B4-B7
Information not in medical records

B4.
Date of urodynamic study: _____ (mm-dd-yyyy)

B5.
Findings of urodynamic study (*check all that apply*):
Good compliance
Poor compliance
Over-activity
Leak point pressure greater than 40
Incontinent/leaking
Detrusor sphincter dyssenergia
Information not in medical records

B6.
Bladder capacity as % of predicted capacity _____
Information not in medical records

B7.
Total number of urodynamic studies _____

COLLECT INFORMATION FOR EACH URODYNAMIC STUDY. IF MORE THAN ONE, USE ADDITIONAL FORM (I.E., COPY OF SAME FORM)

Kidney Anatomy

B8.
Kidney abnormalities noted?
Yes, _____ (mm-dd-yyyy)
*Specify*_____
_____
_____
_____

No
Information not in medical records

Urinary Tract Conditions

B9.
Diagnosis of urinary tract infection (UTI)?
Yes, _____ (mm-dd-yyyy)
No SKIP B10-B13
Information not in medical records or "None noted"

B10.
Type of organism _____
Information not in medical records

B11.
Who made the diagnosis?
Pediatric urologist
Pediatrician
Primary care physician
Emergency room physician
Other, *specify*_____
Information not in medical records

B12.
What symptoms were present? (*check all that apply*)
Fever greater than 101degrees
Nausea/vomiting
Headaches
Fatigue/malaise
Change in cathing schedule
Change in voiding pattern
Foul smelling urine
Other, *specify*_____
Information not in medical records

B13.
Total number of urinary tract infections _____

COLLECT INFORMATION FOR EACH URINARY TRACT INFECTION. IF MORE THAN ONE USE ADDITIONAL FORM (I.E., COPY OF SAME FORM)

B14.
Diagnosis of vesicoureteral reflux (VUR)?
Yes, _____ (mm-dd-yyyy)

No SKIP B15-B20
Information not in medical records

B15.
Was the vesicoureteral reflux
Bilateral
Unilateral
Information not in medical records

B16.
Was a voiding cysto-urethrogram (VCUG) performed?
Yes, _____ (mm-dd-yyyy)
No SKIP B17
Information not in medical records

B17.
Was the bladder neck
Open
Closed
Information not in medical records

B18.
What was the voided residual amount? _____ Information not in medical records

B19.
What was the reflux grade on the right side?
Grade 1
Grade 2
Grade 3
Grade 4
Grade 5
Information not in medical records

B20.
What was the reflux grade on the left side?
Grade 1
Grade 2
Grade 3
Grade 4
Grade 5
Information not in medical records

Procedures

B21.
Have there been any surgeries related to urology?

Yes
No SKIP B22
Information not in medical records

B22.
Type of surgery *(note multiple dates if applicable)*

Bladder Augmentation _____ (mm-dd-yyyy)
What type of bladder augmentation?
Colon
Ileocytoplasty
Ureter
Stomach
Other, specify_____
Information not in medical records

Mitrofanoff _____ (mm-dd-yyyy)

Vesicostomy _____ (mm-dd-yyyy)

Reimplant Ureter(s) _____ (mm-dd-yyyy)

_____ (mm-dd-yyyy)

Sphincter Tightening _____ (mm-dd-yyyy)

_____ (mm-dd-yyyy)

Other Urologic Surgery _____ (mm-dd-yyyy)

Specify_____
_____
_____

Imaging

B23.
Has imaging been performed?
Yes
No SKIP B24-B29
Information not in medical records

B24.
Date of imaging: _____ (mm-dd-yyyy)

B25.

Ultrasonography
Nuclear imaging
Dimercaptosuccinic acid scintigraphy (DMSA)
Magnetic Resonance Imaging (MRI)
Other, *specify*_____
Information not in medical records

B26.
What area was x-rayed?

Bladder
Kidney
Ureter
Other, *specify*_____
Information not in medical records

Imaging Results
B27.
Kidney/s

Hydronephrosis
Normal size for age
Scarring
Other, *specify*_____
Information not in medical records

B28.
Bladder

Thick wall
Trabeculated
Other, *specify*_____
Information not in medical records

B29.
Total number of times for urology related imaging _____

COLLECT INFORMATION FOR EACH IMAGE. IF MORE THAN ONE USE ADDITIONAL FORM (I.E., COPY OF SAME FORM)

B30.
Has serum creatinine been measured?

Yes
No SKIP B31-B32

Information not in medical records

B31.
Date of serum creatinine: _____ (mm-dd-yyyy)

B32.
Serum creatinine value: Level _____

Normal
Abnormal
Information not in medical records

Continence
Urinary

B33.
Does child wear diapers?

Yes
No
Information not in medical records

B34.
Is the child continent (without diapers)?

Continence defined as "Dry, with or without interventions during the day"

Yes
No
Information not in medical records

B35.
Does child use bladder management?

Yes
No SKIP B36-B38
Information not in medical records

B36.
What type of bladder management is/are being used? (*check all that apply*)

Normal void
Clean Intermittent Catheterization (CIC)
Dribble
Crede
Indwelling catheter
Other, *specify* _____
Information not in medical records

B37.

What date was the child/family introduced to a bladder management program/s?
Date introduced _____ (mm-dd-yyyy)
Information not in medical records
Type of bladder management_____

B38.
Who is primarily responsible for the bladder management program?

Child only

At what age did child start performing bladder management program independently?_____

Information not in medical records

Caregiver

Other/s_____

Primarily the child, but others also

Does not apply

Information not in medical records

Continence
Bowel

B39.
Is the child continent and not using a diaper (i.e., no accidents)?

Yes

No SKIP B40-B41

Information not in medical records

B40.
What type of bowel management is being used (*check all that apply*)?

None, voluntary control (normal)

Involuntary, use diaper or pad

Regular scheduled bowel movements with aids used (enemas, digital stimulation, suppositories, etc.)

Regular scheduled bowel movements with no aids used

Percutaneous Cecostomy or colostomy

Other, *specify* _____

Information not in medical records

B41.
Who is primarily responsible for the bowel management program?

Child only,

At what age did child start performing bowel management program independently?_____

Information not in medical records

Caregiver

Other/s_____
Primarily the child, but others also
Does not apply
Information not in medical records

B42. ***Notes/Comments Related to Urology:***

_____

_____

_____

_____

_____

_____

_____

_____

_____

SECTION C: ORTHOPEDICS & MOBILITY

Overall Functioning & Mobility

C1. Level of lesion reported: _____
Information not in medical records

C2.
At what age did the child start to cruise? _____ (give date if available)
Child did not cruise
Information not in medical records

C3.
At what age did the child start to sit? _____ (give date if available)
Child did not sit
Information not in medical records

C4.
At what age did the child start to walk? _____ (give date if available)
Child does not walk

Information not in medical records

C5.
What is the child's mobility status? *check all that apply*

Full-time Independent
with assistive device
without assistive device
Household ambulator
Non-functional ambulator
Non-ambulators
Information not in medical records
Information regarding the child's mobility status does not comply with the Hoffer classification used above. *Please write down the information related to the child's mobility status that is noted in the child's record*:_____
_____
_____
_____
_____
_____
_____
_____

C6. Does the child use assistive technology?

Yes
No SKIP C7
Information not in medical records

C7. What assistive technology does the child use? *check all that apply*

Standing frame/wheeled stander
Reciprocating Gait Orthosis（RGO)
Hip-knee-ankle-foot-orthosis (HKAFO)
Knee-ankle-foot-orthosis (KAFO)
Ankle Foot Orthosis（AFO)
Walker, *specify type of walker*_____
forward/reversed
reversed K-walker
wheeled
unwheeled
Crutches, *specify type of walker*_____
Other/s, please specify _____

Information not in medical records

Conditions & Procedures

C8.
Diagnosis of **scoliosis**?

Yes, *date of diagnosis* _____ (mm-dd-yyyy)
No SKIP C9-C14
Information not in medical records

C9. How was the scoliosis diagnosis made?
Diagnosis made clinically
Diagnosis made radiographically
Information not in medical records

C10. Was the scoliosis congenital?
Yes
No
Information not in medical records

C11. What was listed as the cause/s of the scoliosis?
Chiari II malformation
Tethered cord
Split cord malformation
Syrinx/syringomyelia
Other, specify_____
Information not in medical records

C12. Has the scoliosis been surgically corrected?
Yes, _____ (mm-dd-yyyy)
No SKIP C13-C14
Information not in medical records

C13. Were there complications related to the surgery?
Yes
No SKIP C14
Information not in medical records

C14. What were the complications? *check all that apply*
Infection
Pseudoarthritis arthrosis
Neurological loss of function

Medical complications
Pulmonary complications
Cerebrospinal fluid leak (CSF)
Other, specify_____

C15.
Diagnosis of **kyphosis**?

Yes, *date of diagnosis* _____ (mm-dd-yyyy)
No SKIP C16-C21
Information not in medical records

C16. How was the kyphosis diagnosis made?

Diagnosis made clinically
Diagnosis made radiographically
Information not in medical records

C17. Was the kyphosis congenital?

Yes
No
Information not in medical records

C18. What was listed as the cause/s of the kyphosis?

Chiari II malformation
Tethered cord
Split cord malformation
Syrinx/syringomyelia
Other, specify_____
Information not in medical records

C19. Has the kyphosis been surgically corrected?

Yes, _____ (mm-dd-yyyy)
No SKIP C20-C21
Information not in medical records

C20. Were there complications related to the surgery?

Yes
No SKIP C21
Information not in medical records

C21. What were the complications? *please check all that apply*

Infection
Pseudoarthritis arthrosis

Neurological loss of function
Medical complications
Pulmonary complications
Cerebrospinal fluid leak (CSF)
Other, specify_____
Information not in medical records

C22.
Diagnosis of **hip dislocation**?

Yes, *date of diagnosis* _____ (mm-dd-yyyy)

No SKIP C23-C27
Information not in medical records

C23. Was the hip dislocation

Unilateral
Bilateral

C24. Was the diagnosis of hip dislocation made clinically or radiographically?

Diagnosis made clinically
Diagnosis made radiographically
Information not in medical records

C25. Was the hip dislocation congenital?

Yes
No
Information not in medical records

C26. Was the hip dislocation treated?

Yes
No SKIP C27
Information not in medical records

C27. How was the hip dislocation treated?

Surgically
Non-surgically
Information not in medical records

Knee and Rotational Disorders
C28.

Diagnosis of **foot or ankle deformities**?

Yes, what date _____ (mm-dd-yyyy)
No SKIP C29
Information not in medical records

C29.
Have the **foot or ankle deformities** been surgically corrected?

Yes, what date/s _____ (mm-dd-yyyy)
No
Information not in medical records

SECTION D- HOSPITALIZATION

Neurosurgery

D1. Has the child ever been hospitalized because of **neurological** complications?

Yes
No SKIP D2-D7
Information not in medical records

D2. Dates of **1st** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D3. List reason/s for hospitalization?
_____
_____
_____

D4. Dates of **2nd** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D5. List reason/s for hospitalization?
_____
_____
_____

D6. Dates of **3rd** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D7. List reason/s for hospitalization?
_____
_____
_____

IF MORE THAN 3 HOSPITALIZATIONS USE ADDITIONAL FORM

ATTACHMENT F

Medical Records Data Abstraction Form

Urology

D8. Has the child been hospitalized because of **urological** complications?
Yes
No SKIP D9-D14
Information not in medical records

D9. Dates of **1st** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D10. List reason/s for hospitalization?
_____
_____
_____

D11. Dates of **2nd** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D12. List reason/s for hospitalization?
_____
_____
_____

D13. Dates of **3rd** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D14. List reason/s for hospitalization?
_____
_____
_____

IF MORE THAN 3 HOSPITALIZATIONS USE ADDITIONAL FORM

Orthopedics

D15. Has the child been hospitalized because of complications related to **orthopedics**?
Yes
No SKIP D16-D21
Information not in medical records

D16. Dates of **1st** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D17. List reason/s for hospitalization?

_____
_____
_____

D18. Dates of **2nd** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D19. List reason/s for hospitalization?

_____
_____
_____

D20. Dates of **3rd** hospitalization:_____
(mm-dd-yyyy) (mm-dd-yyyy)

D21. List reason/s for hospitalization?

_____
_____
_____

IF MORE THAN 3 HOSPITALIZATIONS USE ADDITIONAL FORM