



## Spina Bifida Care Outline

### What is Spina Bifida, and why does my child need a Pediatric Urologist?

Spina bifida is a birth defect that affects the development of the baby's spinal cord, spine and developing brain. The defect can take place anywhere along the spine, and causes a portion of the spinal cord and adjacent structures to develop outside the baby's body. This can damage the function of the nerves in the spinal cord, and affect the way the bladder empties. The bladder's two main functions are to store and empty urine – and the nerves help coordinate the different muscles of the urinary tract. When the nerves are damaged, that coordination does not happen, and this can lead to difficulties with potty training, leaking urine, urinary tract infections (UTI) and stones in kidney or bladder. If not well managed, these problems can cause damage to the kidneys. This condition is called a neurogenic bladder.

### How does a Pediatric Urologist manage neurogenic bladder in spina bifida?

*Baseline studies include:*

- Urinalysis and urine culture
- Blood tests for kidney function: Creatinine, BUN, electrolytes, \*B12 (if any surgical reconstruction)
- Kidney bladder ultrasound: checks the size and shape of the bladder and monitors growth of the kidneys. Used to assess fluid on the kidney (hydronephrosis).
- Post-void residual: the amount of urine left in bladder after urination, done by catheterization
- VCUG (voiding cystourethrogram): This test is an x-ray that requires a catheter to be placed in the bladder. It evaluates the urethra, size and shape of the bladder and how well the bladder empties. It will also assess for urinary reflux, which is when urine flows backward from the bladder to the kidneys.
- Renogram: This test is done when your baby is older than 3 weeks of age. It is a test that requires an IV, and a catheter to be placed in the bladder. It is used to see how well each kidney is working and whether urine drains from the kidneys into the bladder without obstruction.
- Urodynamic study (UDS): special study that shows how the bladder works. Requires a catheter in bladder and rectum as well as patches on bottom. It evaluates what pressure the bladder fills, stores and empties urine. It tells us the 4 C's:
  - Capacity – how much the bladder can hold
  - Coordination – how well bladder and sphincter work together
  - Continence – if bladder can hold without leaking
  - Contractions – how often and how strong the bladder squeezes

### Newborns

A renal ultrasound and VCUG are done shortly after birth to learn about the baby's urinary tract system. Based on these results, management will begin. If no reflux or hydronephrosis, and if bladder seems to empty well – nothing special may be needed and baby may wet normally into diapers. If baby has any problems with emptying bladder or fluid on the kidneys (hydronephrosis) or reflux of urine up into the kidneys – a catheterization regimen and medications may be started. An urodynamic study is performed within first few months of life to assess bladder pressure. Sometimes if medicines and catheterization are not enough, a surgical procedure called vesicostomy may be performed to help the bladder empty.



**Infants and Toddlers**

Close monitoring of the infant’s urinary tract is done during first year of life, as things can change as baby grows and develops. Generally, renal ultrasounds every 6 months and urodynamic studies (UDS) annually through age 3. These show how the infant is responding the current care plan. Additional studies may be performed if there are any clinical changes. A catheterized urine culture should be done any time baby has symptoms of UTI (fever, fussiness, poor feeding, and decrease in wet diapers). Baseline kidney function labs should be done around 1 year old.

**Preschool to School age children**

Continued close monitoring is important. Kidney/bladder ultrasounds are obtained every year and urodynamics (UDS) as indicated. Additional studies and office visits if any clinical changes occur such as UTIs, increase in urinary leaking or any problems or concerns. A catheterized urine culture should be done anytime there are signs of UTI (fever, back pain, foul smelling urine, or increase urinary leakage). As child is showing interest in being dry, a urinary continence regimen should be discussed (this may include surgical procedures). Older children may begin self-clean intermittent catheterization (CIC) if they feel ready. Repeat kidney function labs should be done around 5 years old. Bowel issues may also arise and require management.

**Adolescents to Young Adults**

Yearly kidney/bladder ultrasounds and kidney function lab studies should be done with other tests as needed. Urine cultures should be done with any symptoms of UTI. Adolescents should be able to identify their own symptoms, know how to take their medicines, and know their catheterization regimen. Sexual function and expectations should be discussed. Start discussions for transitional care to adult programs and independent/self-management programs for bladder and bowel.

*For any questions or concerns, please call our clinic at 612-813-8000*

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