



Spina Bifida Program
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Welcome

To the **Spina Bifida Program** at Children's National Hospital

Spina Bifida is a life-long condition, and each child is unique. Our Spina Bifida Program will address your child's medical needs as they grow.

Our team:

Hans Pohl, MD	Urologic Surgeon
Briony Varda, MD	Urologic Surgeon
Christina Ho, MD	Urologic Surgeon
Robert Keating, MD	Neurosurgeon
Mi Ran Shin, MD	Pediatric Rehabilitation Specialist
Matthew Oetgen, MD	Orthopedic Surgeon
Celicia Little, DNP, CPNP	Nurse Practitioner
Nicole Allentuck, BSN, RN	Registered Nurse
Christine Scott	Program Associate

Things to Know:

- **Infants & toddlers need to be seen in our clinic every 3-6 months**
- **Children need to be seen in our clinic every year**
- **In some cases, your child may need to be seen more often**
- **To schedule an appointment, call or email:**

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Urology

Urology for the urethra, bladder, ureters and kidneys. They also specialize in bladder function. Urology Goals: **1) Protect the kidneys, 2) Prevent infections, 3) Keep your child dry of urine.**

In your child's **first 5 years of life**, you can expect the following Urology visits and tests:

	Birth	3 months old	6 months old	9 months old	1 year old	2 years old	3 years old	4 years old	5 years old
Team Visit	X	X	X	X	X	X	X	X	X
Lab Studies		X			X	X	X	X	X
Radiology: Ultrasound	X	X	X	X	X	X	X	X	X
Bladder Function: Urodynamics		X			X	X	X		
Radiology: DMSA Study		X							X

After age 5, we will continue yearly clinic visits and ultrasounds. Other studies will be determined by how your child is doing and if any new problems have occurred.

Commonly used Urology medications your child may need:

1. *Bladder Relaxing medications* (like oxybutynin) – Allow your child to safely hold urine
2. *Antibiotics* (like Bactrim) – Prevent urinary tract infections



Clean Intermittent Catheterization

Clean intermittent catheterization (“CIC”):

Most children with Spina Bifida need help with emptying their bladder. Your urologist will determine whether your child would benefit from CIC.

Starting a catheterization program can be a major event. Most parents and children have never had training with catheters, so it is normal if you feel fearful and unprepared. You will soon learn what works best for you and your child. We encourage you to involve your child in the catheterizations at an early age. Staying positive and encouraging your child helps them accept and take part in their care.

What is CIC?

CIC means putting a catheter through your child's urethra into their bladder. Urine then flows out of the catheter. You will do this regularly to completely empty the bladder. CIC can be done to seem like normal voiding. Instead of making a urine stream on their own, your child uses a catheter to make a stream. With practice, the process becomes easier and routine.

Why do CIC?

CIC is used to manage problems with bladder function. It helps prevent infections, damage to the kidneys or bladder, and improves wetting accidents.

How is CIC done?

Male Catheterization

- Wash hands with soap and water.
- Hold the penis with one hand and push the foreskin back if uncircumcised.
- With the other hand, wash the penis with moist cotton balls, a washcloth, or a baby wipe.
- Hold the penis straight with one hand and pick up a clean catheter with the other hand.
- Hold the catheter near the tip.
- Place the catheter tip in lubricant if needed.
- Gently insert the catheter through the opening on the penis until the urine begins to flow.
- If the catheter won't go in, ask your child to take a deep breath to relax his muscles. Rotate the catheter and use gentle, firm pressure to move the catheter in until urine flows.



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- When the urine has stopped, rotate the catheter and remove it slowly. Stop and allow urine to drain from the catheter if urine starts to flow again.
- Return the foreskin over head of the penis if uncircumcised.
- Wash the genital area with soap and water or a baby wipe.
- Wash equipment and lay it out to dry on a clean surface.
- Wash hands well with soap and water.

Female catheterization

- Wash hands with soap and water.
- With your right hand, pick up the catheter and hold it about one inch from the tip.
- Place the catheter tip in lubricant if needed.
- Gently insert the catheter into the urinary opening (meatus) between your left fingers until urine begins to flow.
- Hold the catheter in place until the urine stops flowing. Use your other hand to aim the end of the catheter into the toilet.
- Gently insert the catheter about another 1/2 inch and allow the urine to drain through the catheter.
- When urine has stopped, slowly remove the catheter. Stop and allow urine to drain from the catheter if urine starts to flow again. Hold up both ends of the catheter in your hand to keep urine from spilling on your clothes.
- Wipe your perineum with toilet tissue from front to back.
- Wash equipment and lay it out to dry on a clean surface.
- Wash hands well with soap and water.

How do I get catheters?

We will give you a small number of catheters and supplies after training. We then send a prescription for supplies to the medical supply company, or you can purchase catheters without a prescription at select medical supply stores.



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Neurosurgery

The Neurosurgeon cares for the brain and spinal cord. The goal of neurosurgery care is to protect your child's current abilities and prevent any loss of neurologic function.

There are 3 major components of neurosurgery care for children with Spina Bifida:

Managing **Hydrocephalus**

Hydrocephalus is the buildup of fluid in or around the brain. This can cause increased pressure on the brain that can interfere with normal growth and development. Hydrocephalus is often managed with a shunt, a surgical procedure to allow fluid to flow in the brain.

Managing **Chiari Malformations**

A Chiari malformation is when brain tissue is pushed out of the skull and into the spinal canal. This can block the normal flow of fluid in and around the brain, as well as cause buildup of fluid in the spinal cord (known as a "syrinx"). Almost all children with Spina Bifida have some degree of Chiari malformation.

Identifying and treating **Spinal Cord Tethering**

Spinal cord tethering occurs when the spinal cord is stuck to tissue around the spine. As your child grows, this can stretch the spinal cord and cause damage.

In your child's **first 5 years of life**, you can expect the following Neurosurgical visits & tests:

As a baby:	
If your baby has a shunt...	If your baby does not have a shunt...
Visits every 6 months for the first 2 years then yearly	Visits every 3 months
Baseline MRI (a radiology test of the brain and spinal cord)	Baseline MRI of the brain and spinal cord

As a child:

Routine visits with your neurosurgeon each year
MRI of the brain and spinal cord if your child develops signs or symptoms of a change



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Neurosurgeons also rely on your observations of your child. Symptoms of a neurologic change may include headaches, neck pain, back pain, balance problems, dizziness, weakness, numbness or tingling in the legs, vision problems, weak cry, trouble swallowing, problems with the tongue, breathing problems (especially during sleep).



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Physical Medicine and Rehabilitation (PM&R)

PM&R focuses on muscle function, joint range of motion, preventing skin breakdowns, quality of life and function (ability to dress, feed, walk, clean(bath/shower), thinking) of the child. The goal of PM&R is to improve the function of your child i.e. age-appropriate independence and to promote age-appropriate development.

PM&R care varies based on the assessment of the child's strength, cognition, age, sensation, and function. There are 4 major components of PMR care for children with Spina Bifida:

1. Development and function

Spina bifida affects strength and sensation of the legs and sometimes trunk(chest) and arms. It can also affect thinking skills (cognition). These can cause developmental delays.

2. Orthoses/Braces

Muscle weakness secondary to Spina Bifida most likely will stay the same. Often braces are used to provide support while they walk, move about, or to maintain their joint ranges of motion. PMR will evaluate if braces are needed to maximize a child's function.

3. Equipment

Many children with spina bifida need wheelchairs, especially for long distances. PMR will also assess any equipment needs such as a wheelchair, or bath chair.

4. Therapy needs

Many children with spina bifida need physical, occupational, and speech therapy to promote development. PMR will prescribe the appropriate therapy for your child's needs.

5. School Support

PM&R will advocate for your child to get school therapy services and can communicate with the school about including these therapies.

You can expect the following PM&R visits according to the child's age:

- Every 3 months before the age of 2
- Every 4-6 months between 2-5 years
- Every 6-12 months between 6-10 years

For each visit with PM&R please bring all the braces with you so we can assess whether the brace is safe and appropriate.



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Orthopedics

Orthopedic problems are common in patients with Spina Bifida and can affect the legs, feet, hips, and spine. Some children are born with orthopedic issues, and some develop as they grow. Consistent follow-up with your child's orthopedic provider will help

- keep your child's spine stable,
- improve growth,
- preserve or improve walking ability
- prevent skin breakdown.

Common orthopedic problems:

Spine

Scoliosis: Abnormal sideways curve of the spine

Kyphosis: Abnormal outward curve of the spine

Hips

Hip dislocation: Complete displacement of the femur from the hip joint

Hip subluxation: Partial displacement of the femur from the hip joint

Legs

Tibial torsion: Inward twisting of the shin bone

Knee contractures: Caused by stiffness of the ligaments and tendons in the knee

Feet

Clubbed foot: Abnormal inward twisting of the foot

Vertical talus: Abnormally flexed foot; "rocker bottom appearance

Your child's orthopedic provider may use radiographic tests to assess your child's orthopedic needs.

Common radiographic tests:



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Computed Tomography (CT) Scan: A CT uses advanced X-ray technology to produce detailed pictures of inside your child's body

X-ray: An x-ray is a commonly used, quick, and painless test to see structures inside the body such as bones



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Bowel Management

Your child may struggle with having bowel movements throughout their lifetime. These issues might include a combination of constipation and stooling (pooping) accidents, also referred to as fecal incontinence.

Goals of bowel management include prevention of constipation and improvement of fecal continence (no stooling accidents).

Why does my child need bowel management?

Many children with Spina Bifida struggle with fecal incontinence and accidents which can impact their self-esteem. Constipation is very common which can cause pain as well as fecal incontinence.

Is chronic constipation dangerous?

Yes, chronic constipation can cause abdominal pain and decreased appetite which can affect your child's nutrition and growth. Constipation can also put pressure on your child's bladder which may increase symptoms of overactive bladder, cause urine to leak, and increase their risk of urinary tract and kidney infections.

Types of bowel management

Your child's bowel routine is determined by their age, developmental level, and functional ability.

Dietary Changes and Timed Toilet Sitting: Helpful in children with rectal sensation and sphincter control



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Oral Laxatives:	Miralax Senna (Brand Name: ExLax)
Rectal Enemas:	Saline and Glycerin enemas
Peristeen Anal Irrigation System	Uses a large volume of fluid to clean out the colon
Antegrade Enemas:	Surgical intervention to help flush colon from a small opening in the abdomen
Malone Antegrade Cecostomy Enema (MACE)	
Cecostomy	



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Resources to Check Out:

The Spina Bifida Association (Family resources in English & Spanish)

www.spinabifidaassociation.org

The Center for Disease Control Spina Bifida Page (Family Resources in English & Spanish)

<https://www.cdc.gov/ncbddd/spinabifida/index.html>

NIH Webpage on Urodynamics

<https://www.niddk.nih.gov/health-information/diagnostic-tests/urodynamic-testing>

Family friendly descriptions of CNMC's radiology studies:

<https://childrensnational.org/departments/diagnostic-imaging-and-radiology/resources-for-families>