

SpinaBifida / Myelomeningocele / Neurogenic Bladder

What is Spina Bifida?

Spina Bifida is a birth defect that affects the development of the baby's spinal cord, spine, and developing brain. The most common and most severe form of spina bifida is called Myelomeningocele. The abnormality can take place anywhere along the spine, and it causes a portion of the spinal cord and adjacent structures to develop outside, instead of inside, the baby's body.

How is it repaired?

Surgery to repair and close the defect is usually performed within 24-72 hours of the baby's birth.

How does Spina Bifida affect my baby's bladder?

Children born with Spina Bifida are almost always found to have a neurogenic bladder. This is because the nerves in the spinal cord that control the bladder did not form properly. This means that the bladder will have trouble storing urine in the bladder, emptying the bladder, or both. Almost all children with Spina Bifida require lifelong clean intermittent catheterization (see Clean Intermittent Catheterization section) to protect their kidneys, prevent urinary tract infection (see Urinary Tract Infection section) and allow them to wear underwear. Many children with Spina Bifida also require a medicine for their bladder called an anticholinergicthat will help relax their bladder so that it may store more urine and also protect the kidneys.

How does Spina Bifida affect my baby's bowels?

The majority of children born with Spina Bifida are at risk for constipation because the nerves that regulate the bowel often do not form properly.

This typically does not become an issue until your child begins solid foods. Many babies and children with Spina Bifida require the help of a laxative to keep them stooling regularly. Prevention of constipation is essential for eventually attaining stool continence.

Will my child require surgery for their bladder or bowels?

Many children with Spina Bifida have a very poorly functioning bladder, or a bladder that does not grow with them. When clean intermittent catheterization and bladder medicine is not enough, some of these children go on to require a bladder augmentation. This is an operation that uses a piece of the small intestine to make the bladder bigger (see Bladder Augmentation section).

Children with Spina Bifida also sometimes may have a difficult time becoming continent of stool. While many are able to achieve this with a strict bowel program utilizing medication and potty sits, some families elect to undergo surgery for an Ace Malone which is a way to become continent of stool after other methods have failed (see Ace Malone Surgery section).

What types of tests will my child need for their kidneys and bladder?

After your child is born and discharged from the hospital, they will undergo their first urodynamic evaluation. This test will be performed periodically to evaluate how your child's bladder is functioning and to determine if we are managing the bladder appropriately. Please refer to the section on Urodynamic Evaluation for more information.

Children born with Spina Bifida also undergo regular ultrasounds of their kidneys and bladder to help make sure the bladder is being treated sufficiently and the kidneys appear healthy.

What is UCSF's Spina Bifida Program?

UCSF's Spina Bifida program us is one of only a few programs in Northern California to offer a comprehensive medical and social support for the treatment of infants, children and adolescents with spina bifida and other spinal birth defects involving exposed vertebrae. UCSF's multidisciplinary clinic provides care from medical professionals including those in neurosurgery, urology, orthopedics, pediatric physical medicine and rehabilitation, pediatric development and behavior, nutrition, nursing and social work.

From a urologic standpoint, our goals for your child include: 1) protect their kidneys, 2) attain urine and stool continence, and 3) help your child to become as independent as they can with their urologic routine.

For more information about Spina Bifida please visit the website for the Spina Bifida Association at: http://spinabifidaassociation.org/

See the next page for contact information.

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