Myelomeningocele is a defect of the spine, and of the passage inside the spine called the spinal canal. It can occur at any point along the spine. During early fetal development, the spine comes together like a zipper covering the spinal cord and nerves. Incomplete closure of the spine is referred to as spina bifida, or a neural tube defect.

Myelomeningocele is the most common form of spina bifida in which the spinal cord and the tissue around the cord (meninges) protrude from the baby’s back and are contained in a fluid filled sac. There is no skin covering the defect. This type of defect happens in about 1 in every 1,000 pregnancies. Taking folic acid (vitamin B9) before pregnancy has reduced the frequency of this birth defect.

There are other types of spinal bifida as well, all involving a bony defect in the vertebral bodies. Meningocele is another common form similar to myelomeningocele in that a sac is covering the bony defect without skin covering it. However, in meningocele, the spinal cord is not involved. A third form of spina bifida, myeloschisis, is a bony defect involving the spinal cord without a covering sac. A fourth, less severe form of bony defect is spina bifida occulta. This involves a bony defect with skin covering the defect and usually has a normal spinal cord. While most of the spina bifida occulta cases do not need surgical repair before or after birth, the first three types (meningocele, myelomeningocele, and myeloschisis) will require surgery to repair. Myelomeningocele and myeloschisis may benefit from fetal surgery performed before 26 weeks.

Michigan Medicine’s Fetal Diagnosis and Treatment Center (FDTC) is a leader in the diagnosis, treatment, and management of myelomeningocele.

- Our FDTC specializes in prenatal diagnosis, management, and treatment before a child is born.
- Our multidisciplinary Spina Bifida Clinic, led by one of the nation’s top pediatric neurosurgery programs according to U.S. News & World Report, combines the expertise of our neurosurgery, orthopedics, urology, physical therapy and other pediatric subspecialties to address the complex needs of patients with these congenital spinal cord abnormalities after birth.

Together, these seamlessly linked programs offer fully integrated care for families, ensuring individualized, coordinated care for children with myelomeningocele and their families.

**Fetal diagnosis of myelomeningocele**

Many women have a prenatal blood test during the second trimester. This test is called a quadruple screen (quad screen). It is a screening tool doctors use to check for fetal problems. One of the blood levels this test checks is called AFP (alpha-fetoprotein). This level will be higher than normal if there is an opening in the spine, or in another area of the baby’s body. This lab result, with an ultrasound, detects over 90% of babies affected with a neural tube defect.
An amniocentesis is recommended for fetuses diagnosed with myelomeningocele. There is an increased chance of chromosomal problems with this defect. A fetal echocardiogram is recommended when there is suspicion of a heart defect.

A fetal MRI may be used to further assess the brain and spine when more information is needed.

**Fetal treatment of myelomeningocele**

Fetal treatment is available for a select group of mothers and babies. Findings from a multi-hospital clinical trial in 2010, The Management of Myelomeningocele Study (MOMS), found clear benefits to fetal surgery for babies with myelomeningocele compared to standard postnatal treatment:

- Decreased need for a shunt to alleviate fluid build-up in the brain by the age of 12 months
- Improved scores on developmental testing for both mental and motor function at 30 months of age, dependent on the location of the defect

Fetal surgery for spina bifida involves covering the myelomeningocele with multiple layers of the fetus’ own tissue, or a special skin patch, during the mother’s pregnancy. This procedure offers a rare opportunity to improve the outcome for the developing baby. As with any fetal surgery, the potential benefits must be weighed against the possible risks for both mother and baby.

Michigan Medicine’s FDTC follows criteria established by the MOMS trial to determine if a patient is a candidate for fetal surgery. A complete fetal evaluation will be conducted, which involves an ultrasound, fetal echocardiogram, and fetal MRI performed at our center. Candidates meeting inclusion criteria will meet with our multidisciplinary team, including maternal fetal medicine, neurosurgery, anesthesia, neonatology, and social work to discuss the procedure along with its risks and benefits.

Fetal surgery of this type requires a team of highly skilled professionals in a variety of specialties. At Michigan Medicine, families have the confidence of receiving treatment at one of the few centers in the U.S. where the birth center and children’s hospital are located in the same building, allowing for advanced care for neonates immediately upon delivery and enabling mother and baby increased access for the duration of their care.

Our fetal myelomeningocele program draws upon the full resources of Michigan Medicine’s C.S. Mott Children’s Hospital, bringing together our renowned maternal fetal medicine and fetal surgery teams with our accomplished pediatric neurosurgery team to provide deep experience and a broad spectrum of expertise for each patient.

**Management of pregnancy**

Regular ultrasounds are used to monitor the baby’s overall growth and well-being. These are scheduled every few weeks as the pregnancy progresses. Other antenatal testing may be needed if there other findings or for obstetrical reasons. Delivery is usually planned around 39 or 40 weeks for those whose baby is having a postnatal repair. Mothers choosing in utero repair should expect weekly ultrasound assessments. A Cesarean delivery is scheduled at approximately 37 weeks gestation, or when optimal for maternal-fetal well-being.

**Delivery of a baby with myelomeningocele**

The delivery of a baby with any type of spina bifida should be at a hospital that is prepared for high-risk births, including immediate access to a newborn intensive care unit (NICU) and pediatric surgical services. This will simplify communication between obstetrical, neonatal and pediatric surgical teams as well as limit the separation between mother and baby.

Michigan Medicine is one of only a few centers nationwide at which the birth center is co-located within a comprehensive children's hospital. This unique setting allows for seamless integration between our private-room birth center, state-of-the-art NICU, and access to around-the-clock pediatric surgical services in one convenient location.

The method of delivery for babies with a myelomeningocele remains under debate. There is no clear evidence that having a cesarean section will improve the outcome of these babies. However, a cesarean section may be needed for an obstetrical reason, such as for a baby with very large ventricles who has an increased head circumference. A vaginal delivery is recommended whenever it is a safe option.
Postnatal treatment for myelomeningocele

The majority of babies with spina bifida are repaired after birth. It is important that the baby be handled carefully to protect the exposed spinal cord. This may include using a protective device and special positioning. An operation to close the defect will be done within the first 48 hours to preserve the neural tissue and to prevent infection.

About 80% of the babies develop increased fluid around the brain after surgery. This increased fluid around the brain is called hydrocephalus. When this happens, a second operation is needed to reduce pressure caused by the fluid. With this surgery, a small drainage tube (shunt) is placed to redirect the extra fluid. This tube is called a ventricular peritoneal shunt, or VP shunt.

Antibiotics are given to prevent infections. The most common places infection occurs in these babies are the protective lining of the cord (meninges) and the urinary tract.

In general, the location of the defect generally determines the level of function to the lower parts of the body. These children often require lifelong assistance and the guidance from multiple specialties. Some common problems include bladder and bowel training, reduced muscle strength, and mobility issues.

Some children may have some degree of learning disability.

Latex allergies are more common with these children. This is because they need many operations and procedures throughout their lifetime. Latex items of any kind should be removed from the environment beginning at birth. C.S. Mott Children’s Hospital takes this precaution very seriously, removing all latex products from the operating room environment.

As children with myelomeningocele grow, we offer seamless transition to our multidisciplinary Spina Bifida Clinic, led by one of the nation’s top pediatric neurosurgery programs according to U.S. News & World Report. The Spina Bifida Clinic at Michigan Medicine combines the expertise of the Departments of Neurosurgery, Pediatrics, Orthopaedics, Urology, Physical Medicine and Rehabilitation, and other specialties to address the multiple medical needs of patients with these congenital spinal cord abnormalities. This multidisciplinary approach ensures that optimal and individualized care is provided to each patient in a regular and timely fashion.

Future pregnancy risk

Myelomeningocele is related to many factors. The chance of it happening again in another pregnancy is around 3-5%. Those who have a family history of spina bifida have a higher chance of recurrence.

Folic acid (vitamin B9), should be increased before pregnancy if there is a family history. It is recommended that women planning a pregnancy take 4mg of folic acid each day before conception.

The recurrent risk is different if the defect is related to a chromosomal problem. Your doctor and genetic counselor will discuss the risk in your family.

Make an appointment

For more information or to schedule an appointment, call 734-763-6295.