OUTCOMES

• **Primary**: Convey information about spina bifida in a value neutral, collaborative manner, seeking from families a sense of their background, values and beliefs

• **Secondary**: Provide education regarding all treatment options available to women carrying infants affected by spina bifida, including antenatal repair, postnatal repair and palliation

• **Tertiary**: Provide families with information about providers and resources that will assist in the caring for their child with spina bifida.

Clinical Questions:

1. What are the essential treatment options that are to be discussed for as part of the antenatal consultation for a family with a fetus affected by a NTD?

**Guidelines:**

All available, evidence based treatment options should be reviewed with the family, including antenatal repair.

• Treatment options to be reviewed should include antenatal repair, offered at treatment centers with expertise in the surgical and obstetrical management.[1]

• Antenatal repair and the details of the surgical and obstetrical impacts should be reviewed by surgeons/obstetricians with experience managing high risk pregnancies and/or providing care to infants with NTDs.[2, 3]
• Treatment options should also include repair at birth and a review of what to expect, timing of closure that is ideal (earlier is best).[4]
• In utero palliation/termination of pregnancy should also be reviewed as an option to a family.[2]

2. What are the essential components of prenatal consultation for any child affected by a potentially disabling condition?

Guidelines:
The core component of consultation is a collaborative model with the medical team and parents.

• Survival and spectrum of outcomes (neurosurgical, cognitive, developmental, urologic, orthopedic, dermatologic) for children with NTD’s is expected critical information.[5]
• The information on outcomes should be provided with a lifespan approach.[6]
• Difficulty with specific predictions based on lesion level should be reviewed but general principles associated with lesion levels can be reviewed.[5]
• A review of antenatal testing and results should be offered to clarify any misunderstandings or confusion that may exist.[7]
• Treatment options for associated conditions of NTDs should be reviewed with an emphasis on functional outcome.[8]
• Resources should be reviewed and provided to families, including local, national, and international resources.[7]
• What to expect at the birth can be valuable information and should be offered, including need to have specialists at delivery, examine child, possibility of need for intravenous fluids/antibiotics, and the possibility of the child needing additional support.
• The likelihood that the child will be admitted to a special care or intensive care nursery should be reviewed.
• If not repaired in utero, the timing of referral and/or repair should be reviewed, as well as the stages of repair, with the first step being the spinal defect followed by attention to hydrocephalus as indicated.

3. Are there critical language elements to be considered?

Guidelines:
Consults should avoid the use of words that assign value or bias, including risk, bad news, bad outcomes and should endorse the use of words that impart the importance of the decision including important news, significant outcome, and potential challenges. This allows parents to assign their own values to the news provided.[2,6]
• Reassurance should be provided to the parents that NTDs are not completely understood but that this was not something that was caused by their actions.[7]
• Reassurance should also be provided that while folic acid can help diminish the chance of a pregnancy being affected by NTD, it is not entirely preventative.[9]

4. Are there critical and specific medical providers that should participate in the antenatal consultation for a family affected by a fetus with a NTD?

Guidelines:

Every center is equipped with differing resources but key elements are required in order to provide evidence based, up to date, critical information.

• Fetal medicine and/or obstetrical medicine familiar with managing pregnancies complicated by an antenatal diagnosis of NTD and management of the pregnancy is an essential source of information. These providers are the first line of contact for the consideration to pursue antenatal testing, which again should be offered in a value neutral manner. They are also the first to share the results of the testing.[2]
• Neurosurgery should be a part of the early consultation with the family, to provide information about management approaches, including both repairs at birth and antenatally.[2]
• Clinical geneticists provide important information around the results of testing and the genetics of NTDs.[6,7]
• Developmental Pediatricians focus on childhood disability and how to optimize function. They can provide essential insight with the lifespan perspective as well as functional goals. Developmental pediatricians are also critical to assistance with resource identification, access, and utilization. [9]
• Social workers provide critical emotional support and screening for parental mental health. As such, they should be included in all consultations. They may also provide links to important resources for families, both financial but also emotional support.
• Ancillary consultations with Urology and Orthopedics are very beneficial as they can provide more detailed discussions on interventions available for optimizing functional outcomes.
• A coordinator or navigator (in the role of a nurse or social worker) can be extremely helpful to families as they navigate the myriad of consultations and information gathering and make important, family altering decisions.


