Neural Tube Defect Prevention Program
A Family Story about NTD Prevention

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The Oklahoma Birth Defects Registry staff met Marisa Spannagel when she participated in a consumer input group to help develop materials for women who have had a pregnancy affected by a neural tube defect (NTD). She was tremendously helpful in assuring our materials were sensitive to women who had lost a baby with an NTD. We were extremely moved by her story, and found her courage remarkable. Here is her story:

My husband and I learned that we were going to have a boy in our fifth month of pregnancy; and that same day we learned about something called a neural tube defect, in our case, anencephaly. We should have picked up that something was wrong when our ultrasound technician, about five minutes into our exam, said she had a previous appointment, and left the room. About ten minutes later a different technician finished our exam, and told us we were having a boy. We later learned that the first technician was so emotionally overcome she could not finish the exam. We were immediately sent to our doctor who told us that our son was "incompatible with life." Our doctor encouraged us to terminate our pregnancy, because the birth of an anencephalic baby would be emotionally disturbing. We chose to continue the pregnancy and named our son Scott Walker. We requested a second ultrasound with a doctor, an expert in birth defects, who could further explain our situation. He was the first to recommend that if we wanted to get pregnant again, I would need to take 4 mg of folic acid every day, one month before conception, and the first three months of pregnancy. We were so glad we chose to keep Scott, but it was a difficult time. It is a long walk; going through a pregnancy that you know will end in sadness. I could feel him kicking and moving just like my first daughter Ellen, but this time we were not coming home from the hospital with a baby. Scott was born two months early due to complications in my pregnancy. He was stillborn on January 5th. Thankfully, we had wise nurses who allowed us to spend as much time as we wanted with him in the hospital room. We were able to get plaster imprints of Scott's hands and feet, treasures we will always keep. It wasn't a horrible experience; rather it was a sweet time with Scott, and especially with my husband. Our biggest sorrow was the loss of making memories with our son. Our greatest sources of strength were our faith in knowing that God loved us and was with us throughout our sorrow, as well as the love and support of our friends and family. One of the healthiest ways we handled the grieving process was taking a trip two months later to a favorite place in the mountains where we scattered Scott's ashes. My husband and I cried a lot, but we also felt that we were walking through the entire experience together. It is scary when you start thinking about getting pregnant again, and leaving yourself open to possibly another loss in your life. We did lots of praying, studied about neural tube defects, and asked many questions. It all came down to the same advice; I had to take folic acid. In addition to my prenatal vitamins, I took four 1 milligram tablets of folic acid every day for three months before we even tried to get pregnant. When we did find out that we were pregnant, I alternated between feeling awe that we were having a child, to worrying about our first ultrasound. Our first ultrasound was at about 10 weeks, too early in our baby's development to show if the head was okay. I am not by nature a person who shows anger, but I was so very disappointed and told the technician, "If we can see a pimple on an astronaut's face in space, then surely we could tell if this baby's head was whole!" At our next ultrasound I simply laid on the table, burst into tears, and asked the technician about ten times if our baby's head was fine. She patiently assured me over and over again that our baby's head looked perfect. Our son, Caleb Roy, was born on a very memorable Memorial Day, 2000.

Preconception Care - Important in the Prevention of Birth Defects

The neural tube is the part of the baby that becomes the brain and spinal cord. Development of the neural tube begins at day 17 after conception (about two or three days after the missed menstrual period) and is complete at 26 to 28 days after conception. This 10-day period is frequently before a woman realizes she is pregnant. If the tube fails to develop normally, a neural tube defect (NTD) will occur. NTDs are a major cause of stillbirth, infant death, and lifelong severe handicap. NTDs include anencephaly (no brain), a condition incompatible with life, or spina bifida (an opening in the spine). Sometimes babies are born with both defects. Children with spina bifida can have problems such as paralysis, lack of bowel and bladder control and hydrocephalus.

To prevent NTDs, it is important for every woman of childbearing age to take a multivitamin containing 400 micrograms (0.4 mg) of folic acid *everyday* throughout her childbearing years. Women who have had a previous pregnancy affected by an NTD need to be on a higher dose of folic acid before pregnancy.

Preconception care is an important component in the promotion of healthy families. Women of childbearing age must be aware that NTDs are only prevented when a multivitamin with folic acid is taken in the preconception period (before pregnancy). This is because the neural tube forms before most women realize they are pregnant, and half of all pregnancies in Oklahoma are unplanned.

Provisional data from the Oklahoma Birth Defects Registry has identified the rate of NTDs is steadily declining in Oklahoma, a finding that is consistent with national rates. In 1994, the NTD rate occurred at 0.9 per 1000 births. In 2000, the rate dropped to 0.54 per 1000 live births.

The U.S. Public Health Service has issued two recommendations to prevent NTDs (*Folic* 2):[17]

1. All women of childbearing age who are capable of becoming pregnant need to consume 400 micrograms (0.4 mg) of folic acid every day, even when they are not planning a pregnancy.
2. Women who have had a previous pregnancy affected by an NTD need to consume 400 micrograms (0.4 mg) of folic acid everyday throughout their childbearing years. One month before conception and for the first three months of pregnancy they need to increase the amount of folic acid ten-fold, to 4.0 milligrams each day. This level can only be obtained through a doctor's prescription.

[17] *Folic Acid Now...*