IFSBH GLOBAL PREVENTION INITIATIVE

NEURAL TUBE DEFECTS

Vitabiotics Pregnacare

What are Neural Tube Defects (NTDs)?

NTDs are a group of congenital conditions that occur when the neural tube (which later goes on to form a baby's brain and spine) fails to close completely, leaving a split or gap in the spine. Spina bifida is the most common NTD, with anencephaly being the most severe and incompatible with life. NTDs occur during the first 28 days of pregnancy, before many women even realise that they are pregnant. Any pregnancy could potentially be affected, with around 90% of NTDs occurring where there is no prior family history of the conditions. Approximately 85% of the babies affected by spina bifida will also develop hydrocephalus, 'fluid on the brain' (see our Hydrocephalus fact sheet). Worldwide, over 300,000 babies are born with an NTD very year, with many more thousands of pregnancies also affected that don't reach term, either as a result of miscarriage, stillbirth or termination following prenatal diagnosis. Whilst many babies born with these conditions will receive support and specialist care, and go on to lead happy and fulfilled lives, others are less fortunate, being born without the assurance of even the basics of healthcare and human rights. Although IF advocates for and promotes the many amazing achievements of those living with spina bifida and hydrocephalus, spina bifida is still the most severe congenital anomaly compatible with life.....but, it is also the most preventable. For more information about spina bifida please visit the Centers for Disease Control and Prevention website.

Diagnosis

Although NTDs occur during the first 28 days of pregnancy, spina bifida is not usually diagnosed until a 20 week+ foetal anomaly ultrasound screening, with anencephaly being detectable earlier, from around 11 weeks+ gestation. Prenatal diagnosis provides parents with the heart-breaking choice of whether or not to continue with their pregnancy, and in some countries, up to 80% of affected pregnancies result in late terminations. The reality is, that with effective primary prevention, up to 72% of those pregnancies need never be affected in the first place. However, whilst prenatal scanning and monitoring is taken for granted by many of us, the World Health Organization (WHO) estimates that two-thirds of the global population does not have access to basic radiology services. Without ultrasound, doctors can't monitor pregnancies. This means that the majority of the pregnancies affected by NTDs are not diagnosed prenatally, and are only discovered at, or after birth. Not only does this mean an unexpected shock for parents, but critical, and sometimes fatal delays in obtaining specialist care.

Folic Acid preventable NTDs

Spina bifida is the most severe congenital birth defect compatible with life, but it is also the most preventable. But, NTDs like Spina Bifida and anencephaly are complex, multi-factorial conditions, so it can be very difficult/impossible to determine the exact causal factor (or combination of factors) involved in any particular case. However, we do know that there are a number of key factors that increase the risk of having a pregnancy affected by an NTD, the greatest single risk being insufficient levels of folic acid, both before conception and during early pregnancy.

In 1991, a ground-breaking study was carried out by the Medical Research Council, which proved that taking folic acid preconceptionally and during early pregnancy, reduced the incidence of NTDs by up to 72%. The findings of this large, multi-centre study were so conclusive that the study was stopped early. Once the study had proven beyond all doubt that folic acid was highly effective in reducing the risk of NTD, it was no longer ethical to randomise study participants. This land-mark study forms the basis for the existing WHO recommendation, all country specific recommendations for taking preconceptional folic acid, and mandates for the fortification of staple foods with folic acid all over the world.

Not all NTDs are folic acid preventable, but taking a daily supplement containing 400mcg of folic acid for 2-3 months BEFORE conception, and for the first 3 months of pregnancy, significantly reduces the risk of having an affected pregnancy. Whilst the 400mcg dose of folic acid will meet the needs of most women, some women have an increased risk of NTD and will require a higher dose of folic acid. See our fact sheet on ‘High Risk Women’ to see which women are at higher risk. IF is committed to raising national and global awareness of the importance of Folic Acid as primary means of protection against NTDs.