

Neural Tube Defect Prevention - a Public Health Priority

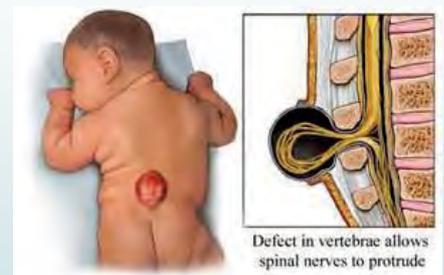
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What Are Neural Tube Defects (NTDs)?

- ▶ NTDs are the most severe congenital birth defect compatible with life. They are also the most preventable.
- ▶ NTDs occur in the first 28 days of pregnancy, before many women even realise that they're pregnant.
- ▶ NTDs affect 1 in 1,000 pregnancies in the UK.
- ▶ Any pregnancy could potentially be affected. 90% of NTDs occur where there is no prior family history.
- ▶ Over 85% of affected babies will also develop hydrocephalus.
- ▶ In the UK, approx 80% of affected pregnancies end in late terminations at 20 weeks+ gestation.



What Does A Diagnosis Mean to Families?

- Having to make heart-breaking and life-changing decisions in a short space of time over half way through a pregnancy.
- Often being made to feel responsible (if they hadn't taken folic acid), when they had no knowledge of it due to lack of education/information.
- Feelings of self blame and guilt.



Obstacles to Prevention

- No robust national strategy on NTD prevention, in line with WHO recommendations.
- Lack of awareness of folic acid, its significance and function.
- Existing information about folic acid firmly associated with pregnancy, missing most of the critical target audience.
- Distinct lack of public health information.
- Inconsistent and insufficient knowledge among front line health professionals (other than midwives who appear too late in the equation).
- No Government Department with responsibility for preconception, so no accountability.
- The fact that 50% of pregnancies in the UK are unplanned.
- Widespread misconceptions about folic acid.



Folic Acid – Perceptions And Misconceptions

- Long held misconception that - Folic acid is something optional that you can choose to take **when you are pregnant, because it's good for the baby**
- Current strategies to reduce nutritional inequalities in more vulnerable lower income groups i.e. Healthy Start Vitamins, have low uptake, reinforce these misconceptions and are not fit for purpose.
- A multi-sectoral approach to achieving; consistency and clarity of messages; a sustained commitment to public health promotion; and preconception education, is key to dispelling these misconceptions.



Are Politics Eclipsing The Issue and Potential Solutions ?

- Has the 20 year + folic acid/fortification debate undermined the importance and credibility of folic acid ?
- First recommendation by the SACN to implement mandatory fortification.
- Re-evaluation by the SACN in response to claims re potential exacerbation of pre-existing cancers, which were subsequently dismissed and the recommendation upheld.
- Waiting for further research papers to be peer reviewed, then waiting (with numerous delays) for latest NDNS data.
- Compelling NDNS data but still no decision on mandatory fortification.
- In the meantime.....No action has been taken in terms of public health promotion of essential preconceptional folic acid supplementation since the 2 year HEA campaign in response to the 1991 MRC study.

The Mandatory Fortification Of Flour With Folic Acid

- Not as simple as following the example of the USA – differences in diet, supplement intake, blood folate levels of the population and target groups and any possibility of excess consumption need to be considered.
- Fortification would help reduce nutritional inequalities in higher risk lower income groups, and help raise base folate levels to help protect against NTD in unplanned pregnancies.
- NDNS data has highlighted widespread folate **deficiency** across at population level, not only within the target group.
- When only an **insufficiency of folate increases NTD risk**, such high levels of recorded **deficiency** in the UK must surely increase concerns.
- Many of the pro-fortification arguments used are unhelpful i.e. women aren't following advice to take folic acid, which is why fortification needs to be considered', and little reinforcement of the fact that there will still be consumer choice - resulting in bad press, negativity and fuelling mass medication arguments.



Supplementation v Fortification – It's Not A Matter of Either Or

- Supplementation with folic acid should be viewed as the primary means of NTD risk reduction, whilst we acknowledge there are certain obstacles to achieving optimum levels of compliance.
- Mandatory fortification should be viewed as a secondary and supporting means of risk reduction, but fortification alone **does not** provide a complete answer to NTD prevention.
- It will raise base folate levels across the population, particularly in low income groups, and help to protect unplanned pregnancies from NTD.
- But.....there are significant dangers if fortification is promoted as a singular NTD risk reduction measure.
- Regardless of any decision on fortification the existing policy re folic acid supplementation will remain the same.



Conclusions: The way forward

- It's not acceptable to do nothing and rely on termination as a form of 'management'.
- **The Government to commit to a robust national strategy on NTD prevention (including education and sustained public health awareness activity), with sustainable outputs and accountability.**
- Develop a multi-sectoral response to a multi-factoral issue.
- We need to focus on the most effective and achievable 'solution' to the issue. Folic acid may not provide the total answer, but maximising the potential 72% risk reduction is a great place to start!
- Strategies to improve overall nutrition of women of childbearing age.
- Support scientific research into additional risk factors.
- Reach a decision on fortification, regardless of what the decision is.



To affect change we need to take action !

*Be part of the solution:
help us spread the word*

