

FINE News

Folate Information Network

December 2008



Wishing you all a happy and safe holiday season and we look forward to bringing you some interesting updates in 2009. The Spina Bifida Foundation of Victoria always welcomes new members and now provides an increased number of programs, activities and publications. If you would like to join or to obtain more information please email fine@sbfv.org.au or call the office on (03) 9663 0075 to talk confidentially.



How have numbers changed for neural tube defects & how has womens' understanding of folate altered in 10 years?

It is well known that the majority of neural tube defects (NTDs) are preventable by adequate folate intake prior to conception and during early pregnancy. The reality is that the average Australian diet contains less than 0.2 mg folate per day and more than 50 percent of pregnancies are unplanned. Obviously this limits the potential impact of advice about diet and a folate supplement in the critical two months prior to conception. It is against this background that health experts and governments have introduced food fortification, voluntary in some countries, like Australia and the United Kingdom and mandatory in countries like the USA and Canada.

Over the past decade Victorian women have had the benefit of voluntary fortification of foods like breakfast cereals (introduced in 1997) and a statewide folate awareness campaign (over 1998), which focussed on the importance of a folate rich diet and promoting a folate supplement to women of childbearing age. Ten years after the introduction of these measures we have studied and published the Victorian data to inform us of how these measures have impacted on the prevalence of pregnancies affected by NTDs, what

the current risk factors are, and the knowledge and understanding Victorian women have of folate related issues.

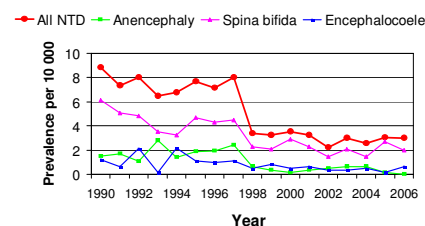
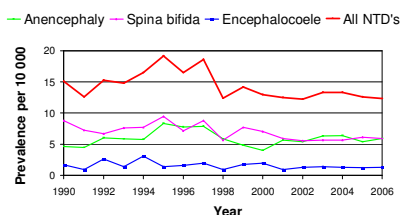


Figure 1 (above) shows the decline in prevalence at birth of babies born with an NTD: there was an approximate 50 percent decline from eight per 10 000 births in 1997 to three per 10 000 births by 1999, coinciding with the introduction of fortification and the awareness campaign. Subsequent to the initial drop, the rate has remained constant.

When we look at the figures for all NTD affected conceptions including miscarriages, terminations and stillbirths, we find a more modest decline from 17 to 13 per 10 000 births between 1996 and 1999, constituting an 18 percent reduction, with no further decline after 1998 (see figure 2 below).



It is clear that the steady rise in termination rate in affected pregnancies (just above 40 percent in 1990 and now about 80 percent) has contributed to the lower live birth prevalence of NTDs. It is important to note that late terminations (more than 20 weeks) and neonatal deaths remain significant in proportion and that only a small number of affected infants have survived beyond the neonatal period.

The recent Victorian study also looked at the risk factors for a woman to have a pregnancy affected by an NTD. It is very clear from the data that younger women (under 30 and certainly under 25 years) are more at risk than women between 30 and 34 years. The odds ratio of 1.65 in the 20 to 24 year old age group says that there is a 65 percent increased likelihood that a woman in this age group will have an NTD affected pregnancy compared with a 30 to 34 year old woman. The value well below 0.05 shows that this likelihood is statistically significant.

Maternal epilepsy carries a statistically non-significant increased risk of 1.5 for an NTD affected pregnancy. This risk is much lower than reported in the previous Victorian study. This may reflect that awareness of the importance of folate in this high risk population has improved, probably amongst women themselves as well as the professionals providing care to this group.

Other risk factors that proved to be non significant were multiple births, urban/rural residence, number of previous pregnancies and maternal country of birth.

Of equal importance and interest are the results of the awareness data, obtained from the 2005 and 2006 Victorian Annual Health and Population Survey. The results clearly indicate that the overall rate of uptake of folic acid supplementation in Victoria remains below 30 percent. This figure correlates with recent figures from South Australia and Western Australia. Younger women are less aware and less likely to take a supplement. Less than half of the surveyed women of childbearing age who were taking a supplement actually knew that the reason for taking folate was to prevent a birth defect. Most see it as important for 'general health' rather than as pregnancy related.

If we put this information in the context of what should be achievable and what has been achieved in other countries, it is clear that there is room for improvement: The Victorian figures have remained static after an initial decline. Our current prevalence of 13 NTDs per 10 000 births remains double that of countries with mandatory fortification (6.8 per 10 000 births in Canada, 5.6 per 10 000 births in USA). The 18 percent reduction in total prevalence of NTDs is far less than in other places. . In the USA the corresponding reduction has been 30 percent, with Canada achieving an impressive 50 percent.

It therefore seems timely that mandatory fortification has been approved for Australia and New Zealand. It is also clear that education needs to remain a focus, as supplementation remains the best strategy to effectively achieve good peri-conceptual folate levels.

It would make sense to target the high risk population, namely younger women in this regard. This type of study also demonstrates the importance of ongoing monitoring to assess whether interventions are actually successful, as well as to monitor for potential side-effects.

*By researchers Louise du Plessis,
Royal Children's Hospital and
Associate Professor Jane Halliday,
Murdoch Children's Research Institute.
The original paper is available on the
SBFV website at www.sbfv.org.au*



Well-being survey

The SBFV is currently trying to find out more about the psychological well-being of people with spina bifida and the types of programs that might provide them with support. We would therefore like to learn more about how having spina bifida, or having a close family member with spina bifida, affects you on a personal level.

If you are interested in providing information to us you can access a short survey via our website (www.sbfv.org.au) which asks a few questions about possible programs. Some of these suggestions are meditation, art therapy, building confidence and self-esteem as well as counselling such as talking in a confidential and supportive group.

We are particularly interested in what activities and interests help people to cope with change; what psycho-social issues or concerns you may have and; what additional activities might be helpful in maintaining your well-being.

This survey can be completed confidentially or you can include your address and contact details so that we can follow you up to provide more information.

Educating GPs

When the SBFV received an invitation to host a free stand at the General Practitioner Conference and Exhibition (GPCE) in mid-November we jumped at the opportunity. Now in its eighth year, the Melbourne GPCE is Australia's premier primary health care conference which has proven to be a unique event that is recognised by GPs as one of the major educational events on their calendar.

The GPCE attracted more than 1,400 delegates from all over Australia and overseas including GPs, Practice Nurses, Academics and other Allied Health Care Professionals. This event provided the SBFV with a really good chance to meet and talk to a diverse range of practitioners and to promote ourselves to them.

From our interactions with health practitioners it is clear that the SBFV still has some work to do in educating people on the importance of folate. The resources we had on hand however were very useful in spreading the word. These resources included the folate and the SBFV brochures, the Community Service Announcements, copies of the health journals and in particular the most recent editions of the Victorian Birth Defects Report and Bulletin. Many visitors to the stand were interested to read about current data and information from the State Register.

Copies of the Victorian Birth Defects Report and the Victorian Birth Defects Bulletin can be ordered from the SBFV office by phoning (03) 9663 0075.