

FINE News

Folate Information Network

June 2008

Promoting periconceptional folate supplementation

Despite evidence that folate supplementation can prevent up to 70 per cent of all cases of neural tube defects (NTDs) like spina bifida, less than 50 per cent of women take folate prior to and during the first three months of pregnancy (periconceptional period).

Danielle Mazza, Associate Professor in the Department of General Practice at Monash University is currently undertaking research with general practitioners (GPs) and women to improve the delivery and uptake of preconception care, including the increase of folate supplementation.

The research project is being carried out in both high and low socio-economic metropolitan areas and rural areas of Victoria.

It involves:

- Focus groups with both women and GPs to determine the barriers and enablers to the delivery and take up of preconception care
- Development of a preconception health care checklist that will assist GPs in providing a comprehensive preconception care consultation
- Development of a GP waiting room poster to increase women's awareness of the

availability of preconception care consultations

- Implementation of both the health checklist and poster (seen below) in the GP setting
- Development and use of a short questionnaire to determine women's knowledge of periconceptional folate use and other key preconception care issues



The project is scheduled to be completed in February 2009, and the findings of the research will be used to improve pregnancy outcomes.

This research is being undertaken with the support of the National Institute of Clinical Studies (NICS) and the HCF Foundation Fellowship. NICS is an institute of the National Health and Medical Research Council (NHMRC), Australia's peak body for supporting health and medical research.

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Promoting the folate message

The SBFV has tried many ways to promote the folate message to as large an audience as possible. We have conducted two successful Folate Breakfasts, distributed brochures and posters and continue to produce newsletters.

Our latest project, which we hope will raise awareness further, is the development of a Community Service Announcement (CSA) featuring Jane Hall (seen below) who is currently starring in the hit TV series Neighbours. As Jane is our Folate Ambassador and experienced behind the camera it made sense to ask her to assist us, which she did most graciously. The result is a professional looking advertisement which we hope that the media will use to help us spread the word about folate.

CSAs are free advertisements which television, radio and movie theatres run from time to time when there's a gap in programming. We're hoping to be lucky and to be aired at popular times.

Keep an eye out and you might just spot us.



A brief history of FINE

It was 11 years ago that the SBFV was granted funding from the Victorian Health Promotion Foundation (also called VicHealth), to create and maintain a database of people in Victoria with spina bifida, or a family history of spina bifida or neural tube defect (NTD). Originally called SPINE (short for **S**pina **B**ifida **I**nformation **N**Etwork), the concept of having a register such as this resulted from discussions between the SBFV and staff from both the Murdoch Childrens Research Institute and the Centre for Child Health, which were conveniently based at the Royal Children's Hospital.

It is important to remember that at this time, back in 1997, there were no folate awareness campaigns in place for the general community or ways for those in the spina bifida community to access up to date health information. In particular, there was no way to communicate to those with spina bifida or a family history of NTD that their folate requirements were 10 times higher than those of the general community. So, together the original SPINE team sought to develop a register of people, to whom information such as this could be targeted.

Specifically, the goals of the SPINE team were to:

- Develop a database/register of people with spina bifida or a family history of NTD in Victoria
- Identify and recruit these individuals and families to the register

- Identify how those on the register prefer to receive health information
- Assess the perceived health information and health service needs of those on the register
- Produce and distribute targeted and appropriate health information materials to the general population.

Over the past 11 years many of the original goals of the SPINE project have been met. For instance, the register has been developed and we are fast approaching our 1,000th member. We have also developed this newsletter and a folate information brochure, specifically targeted to our high risk groups has been developed and printed, and up to date health information, fact sheets and posters are now available on the SBFV website.

Unfortunately, and despite many unsuccessful attempts to gain financial support from the Victorian

Department of Human Services to fund the ongoing recruitment of individuals and families to the register and support its goals, the SPINE project was forced to slow its activities during 2000-2002. Some of you may not have noticed this (we hope you didn't) because we were fortunate to have a team of volunteers behind the scenes recruiting people to the register and maintaining this newsletter.

Then in 2003 the William Buckland Foundation provided funding to continue this project, originally for a three-year period. This support ensured that the project could continue its original goals; then in 2006 SPINE was renamed FINE to better reflect the focus on folate information and to broaden the reach of the project to all families with an NTD. Most recently FINE received funding from the Hugh Williamson Foundation which has enabled it to provide ongoing information to families and to again appoint a part-time Project Officer.

FINE has such a bright future, and for this reason we thought it a great idea to reflect on the achievements of the project. However, our success can only be measured by those on the register, and so we continue to invite you to provide feedback on our newsletter as well as ideas for its contents and the FINE project. Our intention is to provide a register that continues to meet the goals we identified many years ago and provide information that you would like to see.

Data about the register and further information about this project will be provided in the next newsletter.

Free Manual

Passport to success, a manual for young adults about successfully managing incontinence, is available free from the SBFV. To obtain a copy please contact us (as per the details below).

