

FINE News

Folate Information Network

November 2006

SPINE is FINE

Did you notice our name change?

SPINE is now called FINE (Folate Information Network). The new name reflects our focus on folate information and we hope it will also be more welcoming to families with neural tube defects other than spina bifida. FINE News will continue to provide readers with newsletters twice per year, and for people with spina bifida there will be a special *Living with Spina Bifida* section.



Flour Power Update

Health Ministers in Australia and NZ met in October. They are considering mandatory fortification of flour with folate, in consultation with Food Standards Australia & New Zealand. It is not yet known when fortification may happen.

Adding folate to flour will prevent neural tube defects developing in some babies. However because the amount that will probably be added is quite low, it will still be recommended that women who

could become pregnant take a supplement to ensure that they have enough folate. Women at increased risk because of some history in their family or their partner's family will almost certainly need a supplement to obtain the daily 4mg recommended for them.



Survey Results



Thank you thank you thank you to the many people who returned our survey *Has SPINE made a difference to you?*

Your responses tell us about the impact that SPINE has had on people, and will help us improve the information network. Your feedback will also help us report back to The William Buckland Foundation who have provided funding for this project over the last 3 years.

We are currently analysing the results of the survey. At this stage we can say that feedback is generally positive. Many people raised issues or questions which

we will address in coming issues of FINE News. As a direct result of your survey responses, this newsletter includes articles on:

- ~ *Does folate cause neural tube defects?*
- ~ *Does folate increase the odds of twins?*
- ~ *Whose fault is it?*
- ~ *Support after fetal diagnosis of abnormality*



Does lack of folate CAUSE spina bifida or other neural tube defects?

The short answer is 'No, it's not as simple as that'.

The causes of neural tube defects are not completely understood, but there are probably a number of factors which may contribute to causing spina bifida or other neural tube defects. These factors include genetic make-up, lack of folate, and possibly other unknown factors.

As far as folate goes, it has been proven that having enough folate can prevent neural tube defects in up to 70% of babies who would otherwise be expected to be

affected; however in the remaining 30% of babies, the mother's intake of folate does not seem to make any difference. Because of this it is impossible to say in any particular case whether lack of folate contributed to the development of spina bifida, or other neural tube defect.



Does folate increase the chance of twins?



Over the last few years there have been some reports linking folic acid or multivitamin intake to an increase in the chance of having twins.

This year the Public Health Genetics unit at the Murdoch Childrens Research Institute reviewed 12 studies done over the last 12 years to look at this issue.

Overall, the reviewers found that there is *'some possible'* evidence for a relationship between taking folic acid around the time of conception and increased twinning. However, the answer is not clear-cut and the reviewers noted that to clarify the issue, more studies are needed in places where fortification with folic acid has been introduced.



Whose fault is it?

...by Margaret Sahhar,
Senior Social Worker,
Genetic Health Services Victoria

When an unexpected and unwanted event occurs, we usually feel

shocked, fearful, sad and angry. Frequently we also start to wonder "Why?"

"Why did this happen?" can lead to "What did I do to make this happen?" or from others "What did you do to make this happen?"

These reactions are common - the need to either blame another or to take on a feeling of guilt as an explanation. These feelings occur because we need to make sense of what is happening and try to get some order back into our lives.

When a baby is born with an unexpected diagnosis, it is very common for parents and family feel sad, shocked, and fearful for the future. They usually feel a sense of loss for the baby they had expected. Their hopes and expectations for their baby seem to be lost. Family members will share these feelings. Sometimes families have had particular hopes for the baby - that he/she will be a great athlete, a clever scientist, a model, like another member of the family. These hopes may seem to be dashed if the baby has a disability. It can be hard to see beyond the disability to the whole baby who will develop a personality and achieve in different ways.

The sense of loss can be profound and parents and families can start to feel anger that this has happened to them. A common reaction is "Why us? What have we done to deserve this?" Anger is a normal reaction, and a way of expressing the grief and sadness that people find too overwhelming to openly express. Anger may be directed towards the professionals who made the diagnosis, or who care for the baby, towards other family members, towards the healthcare system that cannot

offer enough help etc. Anger can turn to blame and guilt.

Families can blame others in the family. This often occurs when there is a genetic diagnosis. This seems to suggest that there is "bad gene" in the family. Comments such as "It's not in our family" can be hurtful and untrue. They are an attempt to shift blame away from one person onto another - to remove perceived guilt. In situations like this it is important to remember that all of us carry altered genes-nobody is perfect!

The other reaction can be guilt - feeling that you have caused this to happen through some thought or action. Mothers can believe that their actions during pregnancy may have caused the "problem". In the Genetics Clinics at the RCH where we counsel many families who have a child with a genetic diagnosis, we frequently hear this. A parent may take all the responsibility for the baby's diagnosis - usually for reasons that are not valid. People read and hear discussion about causes in the media- drinking coffee, alcohol, eating certain foods, exposing ourselves to chemicals etc. It is hard not to take on some feelings of responsibility. However usually there is no direct link between a parent's actions and the birth of a baby with an unexpected diagnosis. Whilst some popular magazines discuss the power of positive thoughts during pregnancy, research has not found a link between thoughts of pregnant women and their baby's health.

Whilst all these feelings are normal and experienced by many families and parents, it is important to overcome guilt and

not feel blamed. These are negative feelings that can become overwhelming and make it difficult to establish a good relationship with your baby. Excessive feelings of blame and guilt can cause problems between partners and threaten family relationships at a time when support and understanding are needed.

To start to overcome these feelings:

- Talk to your doctor or counsellor to find out information about the condition. If necessary ask that they send you literature or a letter outlining your baby's condition. This can be useful to show to family members.
- What is the cause? Read about the condition, but be careful of the internet where there can be misinformation!
- It may be helpful to join a support group or make contact with another parent. With other parents you can disclose your fears and feelings and be reassured that they will understand and have shared some of your fears and feelings.
- Choose a trusted person to whom you can talk openly. This may be a family member, a friend, or a professional contact.
- Most importantly talk to your partner about your fears and feelings and seek reassurance. Sharing can reduce some of the burden.
- Make time to do things that you enjoy, even if only briefly during each day or a few days each week - start to care for yourself.



Editor's Note: Next year, the Spina Bifida Foundation Victoria (SBFV) would like to run some workshops on the issues covered in the previous article by Margaret Sahhar. The workshops would look at people's feelings about having spina bifida, or about having a family member diagnosed with the condition. If you are interested in taking part or have any suggestions please contact SBFV.

Support After Fetal Diagnosis of Abnormality

...by Alison Thornton,
Associate Genetic Counsellor
Royal Women's Hospital

When a couple is faced with the diagnosis of a fetal abnormality, they can often feel overwhelmed by the testing and decision-making. Events move so fast that there may be no time to reflect fully. The experience may be so profound that it takes months for its meaning to sink in. Family and friends may offer a lot of support at this critical time.

As life moves on, many parents welcome contact with others who have shared similar experiences. It can be helpful to gather with others who understand, to share and reflect on what has happened.

Support After Fetal Diagnosis of Abnormality (SAFDA) is a facilitated shared experience group for women in Victoria who have had a termination for a fetal abnormality. Partners, other family and support people are welcomed. The facilitators

are a social worker and a genetic counsellor. Everything discussed at the meeting is confidential and privacy is respected. SAFDA is held at the Royal Women's Hospital. Five, two-hour groups are held each year with approximately 4-5 persons attending each group.

In addition to existing support, the genetic counsellors are available for individual discussion upon request.

For information about SAFDA, including written resources & support groups, contact genetic counsellors at:

The Royal Women's Hospital
9344 2121

Monash Medical Centre
9594 2026

Mercy Hospital for Women
9270 2394



every single one of you the very best for the future.

Farewell

from Anne Glynn



In 2003 the Spina Bifida Foundation Victoria (SBFV) received 3 years funding to further develop SPINE/FINE. This money enabled a project officer (me) to be employed part-time. Now that the 3 years has passed (so quickly!), it is time for me to move on. The SBFV will keep FINE going through its Education & Communication Officer, **Bianca Montesano**.

I have enjoyed the contact I have had with members of SPINE/FINE and consider myself very lucky to have had such fulfilling work. I would like to take this opportunity to wish

Living with spina bifida

Wallet Card

Did you receive your spina bifida wallet card with this issue of FINE News?

I am a person who has spina bifida

(meningocele, myelomeningocele)

- This card provides information about my medical conditions associated with spina bifida. These are shown inside.
- I can show this card when I see a new doctor or health care professional.
- This card can be kept in my wallet or purse.

The wallet card has been produced by FINE for people with spina bifida or their carers. The Card can be filled in and kept in your wallet or purse so that it can be referred to in an emergency. It can also be a handy reminder of key things to tell a doctor or other health professional who you are seeing for the first time.

When folded, the card easily fits into a wallet or purse. For new or replacement cards contact the SBFV office.



Your Say



If you have something to share with others in FINE, or a suggestion about something you'd like to see covered in a future issue of FINE News...then please give us a call, send an email, or write a letter.

Web Sites



Children with spina bifida

www.waisman.wisc.edu/~rowlev/sb-kids/

A resource page for parents with lots of links to articles and other organisations.

Australian Association for Families of Children with Disability (AAFCD) Provides self-help information, support, and advocacy for families of children and young adults with any type of disability. They have a phone service (1800 222660) which you can ring to find out about key information and support in your area. www.aafcd.org.au

Association for Children with a Disability www.acd.org.au is based in Victoria. Their website has lots of helpful information, including booklets that can be downloaded. These include:

Through the Maze: A Guide This 30 page booklet is a great resource for families of children with a disability who live in Victoria. It contains information on all the different services that can help in each region of Victoria.

Supporting Siblings: When a Brother or Sister has a Disability or Chronic Illness This booklet outlines common sibling responses from early childhood through to adolescence. It focuses on strategies that promote coping and resilience in siblings.

NB Don't forget our own website www.sbfv.org.au which has information and links to useful websites.

Interested in joining the Spina Bifida Foundation of Victoria (SBFV)?

Benefits include:

- *CONTACT* newsletter, every 3 months.
- Social events
- Access to SBFV projects such as the Independence, Computer, and Fitness programs

Membership costs \$35 per year for an individual/family, but a concession is available for those on low incomes.

'NOW' is the perfect time to join, as membership fees are currently being collected for the 2007 year.

Contact the SBFV for more info on 9663 0075 or visit www.sbfv.org.au