

# Gene Advocate



Welcome to the second edition of the Genetic Support Council Western Australia (Inc) newsletter.

As you may have noticed, the newsletter has a new name resulting from our "name the newsletter" competition in the previous edition. The winner of the competition was Mia Ziembski from the Australian Huntington's Disease Association.

As stated in the previous newsletter, each edition we will profile a different genetic support group. This edition, the Spina Bifida Association of Western Australia has been chosen.

## **Spina Bifida Association Western Australia (SBAWA)**

The Spina Bifida Association Western Australia (SBAWA) was formed in 1970 and has since grown in membership to over 100 families. The Association's work centres around a number of objectives:

- To promote and develop the care and welfare of persons with Spina Bifida;
- To promote between members and the public a clearer understanding of the condition and the capabilities of people with the condition;
- Arrange meetings and group activities;
- Make and maintain contacts with similar groups interstate and overseas;

- Enable members to be kept informed as to latest treatment and research; and
- Promote co-operation with the public, hospitals and other organisations concerned with Spina Bifida

Providing support services to individuals and families affected by Spina Bifida is the key role of SBAWA and they fulfil this role by providing services which include:

- Family support
- Family camps
- Community education
- Library
- Tutoring
- Driving lessons
- Fathers and mothers camps
- Young adults programme
- Michelle Foley Memorial Scholarship to university students in their second year of study.



Above: SBAWA activities December 2001

Further information on SBAWA's services can be provided by contacting the Association directly.

## **Upcoming Events**

SBAWA holds their awareness week annually between the 1<sup>st</sup> to 7<sup>th</sup> February each year.

As part of their awareness week, SBAWA hold a 'Sneakers' campaign which aims to raise money for Spina Bifida. Funds raised go towards member services. It is hoped that a fund for research will be established in the near future. The Association has been collecting sneakers signed by celebrities, which come with a certificate of authenticity. These will be auctioned during the awareness week. If you would like any further information on the auction, please contact SBAWA.



Above: SBAWA Activities December 2001

### **Contacting SBAWA**

Oasis Lotteries House  
37 Hampden Road  
NEDLANDS WA 6009

Telephone: (08) 9389 8311

Facsimile: (08) 9389 8331

Email: [sbawa@swannet.com.au](mailto:sbawa@swannet.com.au)

Website: [www.sbawa.asn.au](http://www.sbawa.asn.au)

### **About Spina Bifida**

Spina Bifida is a neural tube defect in which part of the spinal cord or the immediate covering of the spinal cord protrudes through a gap in the spine. Depending on the size of the defect and where it occurs on the back there may be problems which include leg weakness, lack of feeling in the legs, lack of bladder and bowel control, odd shaped feet, dislocated hips and the curvature of the spine.

The consumption of folic acid as primary prevention has been recommended for women of childbearing age.

There are three types of Spina Bifida and it is estimated that around one baby in every thousand is born with one of the other two forms of Spina Bifida. Interestingly, it is also estimated that as many as one person in every ten has a mild form of Spina Bifida known as occulta, and they may never know they have it.

### **Having a child with Spina Bifida**

Vanessa has a four year old daughter with Spina Bifida whose name is Mercedes. At her 16 week Maternal Serum Screening test, doctors detected an elevated protein in Vanessa's blood and sent her for an early ultrasound. At King Edward Memorial Hospital the staff from Genetic Services of Western Australia explained to her what the ultrasounds were looking for, and aimed their information at Vanessa's level of knowledge.

A series of ultrasounds confirmed that Vanessa's child had Spina Bifida. Vanessa's family have a history of being involved in disability services and she was therefore not adversely affected by the news that she may have a child with a disability. For the remaining five months of her pregnancy she actively sought information on Spina Bifida from SBAWA. Vanessa spoke with staff at SBAWA and was invited to come along to a camp to meet some children with Spina Bifida and their parents. Vanessa says this experience provided her with strength and she gained particular inspiration from a 17 year old at the camp who said that the children with Spina Bifida were chosen to live with the condition because "we can take it".

In addition to having Spina Bifida, Mercedes is also epileptic and suffers from autism. She finds therapy and regular hospital visits particularly traumatic. Seeing her child suffer in

this way is obviously difficult for Vanessa, however she also believes that with time parents become able to cope with these negative reactions.

It helps to have networks with other parents of children with Spina Bifida, whom she has made contact with through SBAWA. Vanessa has also been involved in counselling another pregnant woman carrying a child with Spina Bifida, which has led to an ongoing friendship.

### **Folic Acid...**

More information about folic acid intake during pregnancy and its relationship to neural tube defects can be obtained by contacting the Public Health Genomics Branch, Department of Health on telephone (08) 9222 4436 or facsimile (08) 9222 4471.

### **News from the Council**

In January 2002 the interim committee advertised the position of Executive Director for the Council. Applications received were of a very high standard and we are currently in the process of selecting a suitable applicant. The new Executive Director will be in contact with all genetic support groups in the near future.

The Council is also in the process of establishing a web site. It is hoped that this site will be fully operational by the end of April this year. The web site will provide information to the genetic support groups and the community. It will increase community awareness about your specific genetic support group through links to those groups with web sites, and by putting the March 2001 Directory of Genetic Support Groups online.

If you would like further information on the web site, please contact Angela

Rowland on telephone (08) 9222 2231 or email [angela.rowland@health.wa.gov.au](mailto:angela.rowland@health.wa.gov.au).

### **Australian Law Reform Commission Inquiry**

As you may be aware, the Australian Law Reform Commission and the Australian Health Ethics Committee are currently conducting a joint inquiry into the protection of human genetic information. Key issues for the inquiry have been identified in *Issues Paper 26: Protection of Human Genetic Information*, which is available free of charge from the Commission. The Commission's website [www.alrc.gov.au](http://www.alrc.gov.au) is also a particularly useful source of information on this topic.

Earlier in March the Council held a discussion for genetic support groups on this inquiry and the issues it raises. Based on the feedback provided at that discussion, the Council has now made a submission to the inquiry on behalf of Western Australian genetic support groups outlining important issues for the groups.

If you would like a copy of the final submission, please contact Angela Rowland on telephone (08) 9222 2231 or email [angela.rowland@health.wa.gov.au](mailto:angela.rowland@health.wa.gov.au).

We will keep you up to date with future developments from the inquiry.

### **News from the Public Health Genomics Branch**

The Public Health Genomics branch has recently launched the Western Australian Genetics Council and its committees.

The Council and its committees are comprised of experts and will provide advice to the Department of Health on human genetic issues such as policy and purchasing of services, genetic testing, scientific and technical advances, and the legal, ethical and

social issues related to human genetics. The Western Australian Genetics Council will also contribute to informed community debate on these issues.

Project officers have recently been appointed to support the committees, and these are Shannon Clarkson, Sarah Greensmith, Nikki Brehney and Angela Rowland.

**News for the Gene Advocate**

If your support group has any news or upcoming events that you would like to advertise in the Gene Advocate, please forward these items to Angela Rowland and they will be included in the next edition.