



THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC.

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NEWSLETTER

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MISSION STATEMENT

To facilitate support for those affected directly or indirectly by genetic conditions throughout Australasia.

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Contents

Protection of Human Genetic Information – Issues Paper plus Survey for comment.

EDITORIAL

In a few weeks it will be Christmas and you may ask where has the year gone? What a nice change it is to have a Christmas with the magic of Harry Potter washing our worries away with imagery.

I would like to thank you as members of AGSA for your support, donations and help throughout what has been an eventful year for AGSA – the turning point being us receiving our Enhancement Funding. However, before we close down for the year and take a much-needed break I would like to ask one more thing of you.

Please read the following article and fill in the enclosed survey questions, which are prompts to assist you formulating your comments on the Protection of the Human Genetic Information – Issues Paper. The closure date for submissions is 14th January 2002 and AGSA will be writing a submission, which will represent your opinions. I look forward to reading your comments.

Recently I met with a psychologist (see next issue for details) who is very interested in writing a book on the developmental aspects of chromosomal abnormalities. This is very exciting and AGSA looks forward to assisting in this project.

In the New Year 12th-13th January AGSA is holding a Lowe syndrome seminar – the first in Australia so if you know of any families please get them to contact me.

I hope you have a safe and happy holiday break. The office will be closed from 24th December to 11th January 2002.

Until the New Year,

Best wishes for a fantastic Christmas and may 2002 bring you many good things.

Dianne Petrie





MERRY CHRISTMAS

**ATTENTION
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PLEASE READ and complete the enclosed survey, THANK YOU.

The Protection of Human Genetic Information

In February 2001, the federal government asked the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC) to conduct a joint inquiry into genetic testing and information.

The ALRC and AHEC have been asked to consider what sort of regulation may be needed, in relation to human genetic samples and information, to:

- protect privacy;
- provide protection from unfair discrimination; and
- ensure high ethical standards of conduct.

The joint inquiry is considering these primary themes of privacy, discrimination and ethics in relation to a number of contexts in which genetic information may be used including employment, insurance and superannuation, law enforcement and evidence in court proceedings, health administration, medical research and practice, management of human tissue banks and genetic databases; and access to services and entitlements.

When the ALRC and AHEC report to the federal Attorney-General and the Minister for Health in 2002, the inquiry will make a series of recommendations aimed at achieving a proper balance between appropriate access to genetic information and legitimate concerns about ethical

uses, privacy protection and unfair discrimination.

Genetic information inquiry - Issues Paper & public meetings

As the first public step in the inquiry on the protection of human genetic information, the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC) launched a community consultation paper on Wednesday, 14 November, 2001.

The consultation paper *Protection of Human Genetic Information* highlights potential concerns about the use of human genetic samples in areas such as: medical research and practice; tissue banks and genetic databases; health administration; employment; insurance and superannuation; access to services and entitlements; law enforcement and evidence in court.

Issues Paper is free and also available on line at the ALRC website: <http://www.alrc.gov.au>. You can also order a copy of the Issues Paper - either on CD or in hard copy by contacting the commission on <mailto:publications@alrc.gov.au> with your full contact details and specifying whether you would like the CD or hard copy version. ALRC

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The Issues Paper is very long (442 pages), of 14 chapters, but a 14-page summary provides a detailed guide to the areas being examined. The paper contains a background to the inquiry, a study of the current legal, ethical and regulatory systems surrounding the use of human genetic samples and information; a basic educational primer; and targeted questions, designed to prompt community discussion on important issues for the inquiry.

Because genetic information is an area of broad community interest, the inquiry is particularly keen to consult widely and provide all Australians with an opportunity to have their say.

A series of public meetings will be held in major capital and regional cities. Details of these are available on the website or from the Commission.

Submissions to the Inquiry

Comment and submissions on the issues raised in the paper are invited and should be sent to the ALRC. The closing date is very soon (14 January 2002) but I am sure that this will be a bit flexible!

For those who would like to make a personal submission, the paper contains a series of questions that may be helpful to guide you. Any comments do not have to be in a formal manner but can simply be in dot points, etc. The more comments the ALRC receives the more comprehensive will be the discussion paper.

The AGSA committee is also currently preparing a response in conjunction with the Medical and Professional Advisory Board and we would like to reflect the views and concerns of our membership. Inserted with this newsletter is a proforma that may help you to provide AGSA with our views.

It can also be downloaded from AGSA's web site www.agsa-geneticsupport.org.au.

Kris Barlow-Stewart

Member

**Advisory Committee to the Joint Inquiry
Chair**

Medical and Professional Advisory Board

AGSA would like to apologise for omitting to acknowledge that the Triple X syndrome fact sheet in AGSA's October 2001 Newsletter Issue 55 was kindly supplied by the NSW Genetics Education Program.

**Planning Ahead Kit from the
Department of Ageing, Disability
& Home Care**



**Resources for managing financial, health and lifestyle decisions into the future...
August 2001**

The kit can be obtained by phoning 02 9367 6811 or by downloading it from the department's web site at <http://www.add.nsw.gov.au> and click on publications. Also available via e-mail, in Braille, large print, audio and on computer disc on request.

Summer camps for children with ADHD to be held at Macquarie University Sport Centre.

Three camps of one week duration will start on 7th, 14th and 21st January 2002. Ages 6 to 13 years of ages.

For further information contact the Maimonides Global Research Institute, (a non-profit research organisation) on (02) 9402 7354

**Guardianship Tribunal – Seminars 26th
March 2002 at Pennant Hills**

For further details contact the Guardianship Tribunal's Training and Information Branch on (02) 9555 8500.



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