



**Society of  
Bioscience & Technology**

**In Response to the Call for Feedback  
on Genetic Testing and Research (GTR) in  
Singapore**

**Executive Committee  
May 2005**

### 1.0.0 Introduction

We, the Society of Bioscience & Technology provide this feedback with the aim of contributing our views towards the call for feedback pertaining to Genetic Testing and Research (GTR). It is our wish that all policies henceforth formed with regards to the aforementioned are to benefit and protect the citizens of the Republic of Singapore via the safe, effective and ethical application of new genetic knowledge and technologies associated with its use. We hereby strongly advocate the use of human genetics with the highest order of Government regulation to uphold the value and integrity of human life and in addition, to prevent any potential abuse associated with its application that will infringe on human rights or culminate in any discrimination arising from the recourse of eugenics in socio-developments.

### 2.0.0 Background

Ongoing advances in human genetics and technologies will certainly impact Singapore at large. Unequivocally, new sophisticated discoveries arising from the pervasive and specialised use of human genetics in bioscience research will continue to emerge indefinitely throughout this millennium. Some of these will redefine, alter and enhance the limits of medicine in present health-care systems.

As with current advancements in genetics knowledge, it is already impossible to ignore its potential impact and prolific use in bioscience applications that will invariably influence many aspects of daily living; typically in mainstream health-care, drug development in biopharmaceuticals (to provide novel and efficacious pharmacogenetic therapies) and in forensics associated with identity testing in law enforcement. With such an imminent course of revolutionary change, it is therefore, crucial to assemble a clear, relevant and comprehensive legislative framework to identify and assign legally acceptable limits in the use of genetics knowledge and associated technologies. In addition, due to its immense potential benefits it offers to the medical fraternity and the public, it is important that there is a clear understanding in its application and implications by members of the public such that an educated and consentaneous decision can be made pertaining to *de novo* options provided by developments in biotechnology.

At present, genetic testing in clinical laboratories is employed for the following circumstances:

- Diagnosis of individuals with symptomatic conditions of rare inherited disorders.
- Identify individuals with an inherited genetic change that may render them highly susceptible to certain cancers (e.g. breast and bowel cancer).
- Identify the presence of a genetic change in healthy individuals (e.g. Fragile X) that may have specific implications for their offspring and relatives.
- Prenatal screening of foetuses for genetic disorders (e.g. Down's syndrome).
- Neonatal screening of newborn babies for genetic diseases (e.g. Phenylketonuria, PKU).
- To determine if an individual is a carrier of recessive disorder (e.g. Cystic fibrosis, sickle-cell anemia or Tay-Sachs disease) in carrier testing.
- To predict an individual's predisposition to the late-onset of acute diseases (e.g. Huntington's disease) based on family history.
- To resolve ambiguity in legal claims of biological parentage.

- Characterisation of abnormalities such as leukaemias and tumours by analysing acquired genetic changes.

### 3.0.0 Positive implications in the use of Human Genetics.

After fifty years since the discovery of DNA structure as the “molecule and blueprint of life” by Watson and Crick and the landmark success of the Human Genome Project (HGP) in 2000, a revolutionary breakthrough in human genetics propels the world in a number of ways; health-care, biopharmaceutics and economy. Since genetics is associated with various sub-disciplines in the biosciences, similar breakthroughs have been accorded respectively and may eventually leave an indelible impact on humanity, direct or indirectly. Advances in human genetics offer much promise in:

#### Health-care:

Human life expectancy in the modern era has to a large extent, increased due to better nutrition, hygiene and health-care. It is expected that many are able to survive up to the sixth decade of their lives but will however, be encumbered with debilitating illnesses/diseases; hence the compromise on their quality of life. Through the profound knowledge and research in advanced human genetics today, there is strong evidence that in the following few decades, human suffering and distress can be ameliorated while quality of life is enhanced.

Genes in general, form the significant basis of physiological function and disease development. Detection of genes associated with disease by genetic testing is now becoming readily available and can advance understanding of a medical condition. Such tests are not limited to the clinical diagnosis of a symptomatic medical condition or syndrome but are also used to predict in patients and their offspring, the likely development of a specific medical condition. Predictive detection of disease predisposition is advantageous in that, it offers an opportunity for clinical geneticists to provide early monitoring, lifestyle counseling and pre-emptive medical treatment to be employed to avert its onset.

Genetic testing is considered a direct test that is normally performed before and after a medical condition is symptomatic. Such tests often provide diagnostic (e.g. distinguishing different types of leukemia) and prognostic (e.g. identifying the product of a mutated p53 tumor-suppressor gene that flags the likely aggressive growth of cancers) information based on the analysis of DNA structure (cytogenetic testing) or aberrant changes in the DNA sequence itself (molecular testing). However, in recent times, genetic testing is also employed to study acquired changes in cancer tumours. In essence, genetic tests examine genes or human chromosomes for genetic markers that may indicate the presence or susceptibility of diseases or conditions (e.g. breast cancer or Alzheimers); hence the ability to predict the probability of acquiring the disease in the future. In certain instances as in Huntington's disease, a neurologic disorder with late onset, such diagnosis can inform future lifestyle and reproductive decisions.

Present focus in diagnostics for disease prevention of sequenced human genomes has progressed from single-gene disorders to those of major diseases (e.g. cancer and cardiac disease) whereby their etiologies are multifactorial and often include lifestyle and the environment. It is necessary however, to emphasise that a genetic test merely indicates an individual's susceptibility to the disease

personal genomic data also extends to issues pertaining to employment, schools and adoption agencies.

Additionally, other prevailing issues include the likely impact on national security and law enforcement. Since genomic data form the basic molecular blueprint of an individual, such information, when illegally acquired could lead to the demise of innocent individuals who may be wrongfully implicated for crimes committed by another. Similarly, if genomic data is authorised for use as a means of personal identification, doctoring of such identification through the use of illicit genomic data is a possible concern for national security in that "genomic forgery" will replace passport forgery.

Where jurisdictions intend to use such genomic data as criminal evidence in law enforcement, it is imperative that they wait for more advanced methods to provide error-free matches since current methods used to interpret genomic data is still prone to a relatively high percentage of error (DNA profile error rate of 4%) [3, 4] arising from the incidence of human error despite the inclusive use of quality assurance. Furthermore, research into the improvement and agreement in the standardisation of genetic testing methods is also necessary since different test agencies employ different considerations of loci-matching. In addition, there is also a certain discrepancy between results obtained when performing genetic tests using PCR and RFLP techniques. Hence, the subject of GTR remains highly controversial in the abovementioned situations.

#### 5.0.0 Conclusion

In conclusion, we believe that:

- i) **The use of GTR of an individual should be voluntary and not be mandatory; this should apply to Singaporeans, foreigners and foreign workers alike. The latter two being already entitled to their human rights according to their own home countries.**

We disagree with mandatory GTR as we believe that individuals in Singapore should be able to make an elective choice concerning the use of their genetic information for GTR. Due to the sensitive nature of such information, being private and confidential, the need for GTR should only be limited to medical treatment, diagnosis and disease detection/prediction. The individual should be consulted and be able to provide his/her consent after being informed about the intended use of his/her confidential genetic profile.

As in the United Kingdom, GTR in Singapore should similarly be subject to a legal code and remain elective except where a search warrant or court order prevails. At present, the United Kingdom holds the most extensive DNA database in the world (>2 million records) [1] but the endeavours by Biobank, U.K involved in genetic data acquisition and storage have demonstrated the initiative to be resource intensive. In addition, it is found that the cumulative size of the genetic databases comprising sequenced genetic data exceeds its initially projected use that promises useful clinical applications since more developments are yet needed to process and accurately translate the voluminous stored raw data into clinically useful information and therapies [2]. Other issues also need to be addressed; the safe handling (to prevent incidence of test error during analysis) and disposal of DNA after testing.

- ii) **GTR should be employed and limited only to medical genetics research to benefit, improve health-care and for life-saving circumstances via the use of screening and diagnostics in disease predisposition concerning genetic, recessive and inherited disorders (e.g. Cystic Fibrosis and Huntington's disease).**

It is evident that current genetics knowledge can provide a useful basis in disease screening and diagnostics; hence GTR should be used in existing health-care systems to predict in advance, the predisposition of an individual to a disease so that clinical geneticists are able to monitor and counsel the individual to prevent its onset and to allow possible early pharmacologic treatment. There are however, some concerns with regards to the possible psychological impact of employing GTR for such predictive intent as it is likely that the results can psychologically affect the individual. It is therefore, important to implement adequate counseling for pre- and post-testing.

- iii) **Since genetic databases are stored in computer-based systems, they are therefore not tamper-proof as seen in recent cases of security breach involving the remote hacking of highly-secured government agencies. Hence the reliability of such means of genetic data storage is inferior. Additionally, the high expense in terms of resources (mainly time and manpower investment) to acquire such invaluable genetic databases may be easily destroyed by malicious computer viral attacks given the current capabilities.**

- iv) **There should be an independent Non-Governmental Organisation (NGO) to monitor and manage the appropriate use of such sensitive information even if the genetic databases comprise those of volunteers.**

Due to the need to provide sufficient mechanisms to monitor, manage and control the accessibility of such sensitive genetic information, it is necessary to engage the involvement of an NGO. The latter should perform an independent and essential role in ensuring transparency; to provide stringent accounting to the public domain on developments concerning the use of genetic databases and the security safeguards of genetic databases. Additionally, its role also includes the evaluation and monitoring of research developments and provide feedback and education to the public.

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16 May 2005

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Dear Professor Kaan

**Feedback on Consultation Paper**

I refer to your letter dated 4 April 2005 soliciting our comments on a consultation paper 'Ethical, Legal and Social Issues in Genetic Testing and Genetics Research'.

We have studied the consultation paper with great interest and have the following comments:

1. In the section on 'Defining Genetic Testing' (page 4), it is proposed that only testing carried out on DNA, RNA and chromosomes and linkage studies are defined as genetic testing. We feel human leucocyte antigen (HLA) testing using Terasaki microcytotoxicity should be considered a form of genetic testing because it provides information that may be used to infer genetic inheritance. Loosely speaking, this may come under the category of 'linkage studies' in the definition. Regardless, the results of HLA testing using this technique should be kept confidential because they have a bearing on disease predilection and paternity issues.
2. We agree that the results of genetic testing should be accorded the same level of confidentiality as medical information, and special care should be place on sensitive genetic information. We wish to point out that while information that can be draw from a person's entire genetic make-up is vast, doctors usually ask for very specific tests that has limited impact. It is the capacity to perform tests that are not medically indicated on the DNA obtained for legitimate reasons that is has the greatest potential for misuse.
3. In the section 'Specific Ethical Considerations for Human Genetics Research', there are no recommendations on the disposal of genetic material after a research study has been completed. It is possible that researchers may store genetic material. A statement regarding this issue will be very useful.

Best Regards,

A/Prof Philip Choo  
Chairman, Medical Board

My doc/Julie/Bioethics Adv Cttee

Affiliated Teaching Hospital  
of the National University  
of Singapore



A member of National Healthcare Group  
Adding years of healthy life

Dr Amar Bhat Director, Office of Asia and the Pacific U.S. Department of Health and Humans Services
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May 16, 2005

Dr. Sylvia Lim  
Assistant Head, Secretariat  
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Dear Dr. Lim

We at the U.S. Department of Health and Human Services (HHS) have taken the opportunity provided by the Singapore Bioethics Advisory Committee (BAC) to comment on your consultation paper entitled "Ethical, Legal, and Social Issues in Genetic Testing and Genetics Research." These comments were prepared by staff of the HHS Secretary's Advisory Committee on Health, Genetics and Society (SAGHS), with input from representatives of our National Institutes of Health, the Food and Drug Administration, the Centers for Disease Control and Prevention, and the Health Resources and Services Administration.

We commend the efforts of the Human Genetics Subcommittee (HGS) on drafting a thoughtful, comprehensive, and balanced treatment of many of the issues currently surrounding genetic testing and genetic information. The concepts are conveyed with clarity, sensitivity, and an appreciation of the complexities of genetic testing and the clinical, ethical, legal, and social issues related to genetic information. We were also pleased to see clear rationales provided for the recommendations, with numerous references to the work of other advisory bodies and the approaches taken by other countries, suggesting that the HGS considered and built upon the thinking of other nations.

You may already know that the recommendations are mostly consistent with current U.S. policies and standard practices. In some cases the consultation paper goes beyond current U.S. positions. One example is that the HGS has suggested specific policy statements relating to the disclosure of confidential genetic information to an affected family member, and the appropriateness of pre-implantation genetic diagnosis and pre-implantation tissue typing. General matters that HHS has identified in the consultation paper are outlined below. Specific questions and comments about various

sections of the consultation paper are included in the attachment, and offer HHS perspectives and/or note the usefulness of additional clarification about specific issues.

We observed that the document combines the discussion of ethical issues in the research setting and in the clinical care setting into one section, even though there are a number of important ethical concerns that affect these two settings differently. Differences include the range of acceptable informed consent processes, the amount of counseling and other information provided to patients, and the uses of the information gathered from the genetic tests. In some kinds of screening programs or clinical care situations, the emphasis on voluntary participation may be less relevant than it would be in a research setting. Examples include newborn screening programs and urgent care settings, where a rapid diagnostic test is needed in order to ascertain the best treatment for the patient. In a research project, a premium is placed on voluntary participation and consent, and some genetic tests may be used that are not clinically validated and where the specific health implications for the individual are unknown. The use of these tests in a clinical care setting would be entirely inappropriate, but in the research context, there may be scientifically and ethically valid reasons to include these tests. The document would benefit from additional clarity in the treatment of clinical versus research uses of genetic information and testing, and the potential interaction between the two purposes under some circumstances such as when only a research-caliber test is available for a particular disorder. The recommendations would be better served if each recommendation were divided into two sections; alternatively, the research-related recommendations could be incorporated into the section dealing specifically with research. Separate criteria should be laid out for the conditions of use for genetic tests in clinical versus research programs.

Although we recognize that the consultation paper is deliberately limited in scope to genetic testing for certain specified purposes and genetic tests for heritable disorders, the paper should acknowledge that the scope of genetic testing is evolving rapidly. Historically, genetic tests involving DNA, RNA, or proteins have been used to identify single gene disorders caused by germline or heritable variations. However, nowadays the term “genetic test” is often used more broadly to refer to any test performed using molecular biology methods to test DNA or RNA, including heritable and acquired somatic variations. As genomic medicine advances and evolves, with acquired somatic variations evaluated in the context of an individual’s entire genomic variations, the definition of a genetic test may become even broader. We note that there is no reference to pharmacogenomics and its ethical and policy implications. There is also no discussion of genomic research more generally, which differs from single gene testing in its search of the entire genome for variations that have implications for basic genetic processes or human health. The committee should clarify if it intends to address these areas in future work, or if they have been omitted for specific reasons pertaining to the committee’s purview or mandate.

The United States has been considering many of the issues raised in this consultation paper over the past several years. The SACGHS was first established in 2002 to support broad-based public policy development to address the benefits and challenges

of genetic knowledge and genetic testing. Information about SACGHS and current U.S. policy positions can be found at the following website:

<http://www4.od.nih.gov/oba/SACGHS.HTM>

HHS would like to thank you once again for providing the opportunity to comment on this consultation paper. We look forward to working with you as Singapore develops its bioethics policy.

Sincerely,

Amar Bhat, PhD  
Director, Office of Asia and the Pacific

Attachment: Specific HHS Comments and Questions

**Attachment 1**  
***Specific Comments and Questions***  
***Provided by the U.S. Department of Health and Human Services***

**Section I. Introduction**

1.8 The statement that “the conduct of genetic testing should be limited to medical or related purposes” could be read to mean that the BAC believes that genetic testing should not be used for forensic and identification purposes. Assuming this is not the intent, it might be helpful to clarify the meaning of the statement.

**Section II. Genetic Testing and Genetic Information**

2.3 (a) Consider replacing “the definitive genetic cause” with “the genetic basis”

2.3 (c) Consider replacing “genetic disorder” with “genetic mutation”

2.4 Last paragraph, consider replacing part of the sentence beginning “Genetic Testing does not include these methods when they are not...” with “Genetic Testing only includes these methods when they are primarily designed to detect specific genetic defects, rather than to screen for overall biochemical.....”

2.10 Last sentence, consider replacing “accordingly bear ultimate responsibility towards them” with “bear ultimate responsibility with regard to the use of the test and its interpretation.”

**Section III. General Ethical Considerations**

3.2 Note that in the U.S., the term "voluntary" is used rather than "free" when referring to consent.

3.7 In (e), consider including a reference to financial risks of the test result.

3.8 If extra tissue (not just surplus tissue) will be collected for future research, the consent should make this clear.

3.9 Consider adding the following between (c) and (d), “whether or not the test itself is experimental and gives information on what is known about the clinical implications of the test itself, if any; inform as to how the test results relate to the overall purpose of the research.”

3.16 It would be helpful to discuss how a child's understanding will be evaluated and the role of consent monitors in this regard.

3.19 With regard to provisions for genetic testing on persons with impaired mental capacity, it is important to consider medical care situations where information is needed to diagnose and treat a disorder. At times, it may be impossible to obtain the consent of a parent or guardian, and the health of the individual may be at risk. In these settings, the clinical care needs should be distinguished from those of research.

3.24 Since it would be beneficial to further emphasize that full information should be provided to the patient about the urgency of informing others of the test result, prior to overriding this person's wishes, consider adding the following as the first item: "Efforts have already been undertaken to fully educate and explain to the individual the implications of the test results for a third person" and "The genetic information should not be disclosed to others beyond the individuals or entities that need to know in order to avert harm."

#### **Section IV. Public Access to Genetic Testing**

Currently, there is no nationwide consensus in the United States that direct access to genetic tests should be banned or strictly controlled. The American College of Medical Genetics (ACMG), a U.S.-based professional organization representing medical geneticists, issued a policy statement in 2003 discouraging direct access to genetic testing without the involvement of an appropriately qualified health care professional to ensure appropriate use, interpretation, counseling and follow-up. ACMG cautions against self-ordering of genetic tests and use of genetic "home testing" kits due to the complexities of genetic testing and the potential for harm. Yet, many U.S. consumers view direct access to tests and information about tests as empowering, enabling the exercise of greater control over their health and well-being.

In the U.S., States are responsible for controlling who may order laboratory tests, including genetic tests, and who may receive test results. As of 2003, 21 states had no limits on access, 12 allowed limited access and 17 prohibited direct consumer access to laboratory testing. The Food and Drug Administration (FDA) within the Department of Health and Human Services (HHS) and Federal Trade Commission (FTC) both have roles in protecting consumers from false and misleading advertisements in the health care arena, and FTC has a general responsibility for truth-in-advertising in all areas.

SACGHS is addressing direct-to-consumer marketing of genetic tests. In December 2004, the Committee sent a letter to the Secretary expressing concern about the potential harms of direct-to-consumer marketing of genetic tests and recommending that relevant HHS agencies: 1) collaborate with the Federal Trade Commission and provide information about advertisements that could potentially mislead consumers as to the efficacy and safety of genetic tests marketed directly to them; 2) clarify their own roles and responsibilities in monitoring the advertising of genetic tests offered as laboratory services, especially with respect to so called "homebrew" tests; and 3) collect the necessary data and conduct an analysis of the public health impact of direct-to-consumer advertising and direct access to genetic tests. The Committee will be briefed at its upcoming meeting (June 15-16, 2005) about the agencies' efforts.

- 4.2 Consider adding an additional harm: “Misguided reproductive decisions based on misunderstanding or misinformation from a test.”

### **Section V. Specific Ethical Considerations for Human Genetics Research**

- 5.2 Consider replacing “genetic basis of common diseases” with “role of genetic variation in contributing to common diseases.”

### **Section VI. Specific Ethical Considerations for Clinical Genetic Testing**

6.24 U.S. policy also opposes germline genetic modification. However, since the subject of germline genetic modification is, as explicitly noted in 6.25, outside the scope of this report, it is not clear why the topic is included in the document.

6.34 In (b), consider replacing “Such disorders are generally due to the interaction of genes and...” with “Such disorders are often the result of the interaction of multiple genes and environmental factors.”

6.45 Consider adding that laboratories recognize that results may not always be returned to health care providers familiar with genetic principles, and that pertinent information and follow up recommendations (i.e., for genetic counseling) should be made in a useful and comprehensible way. Ideally, adequacy of the reports should be evaluated with both laboratory and health care provider input.

6.47 This paragraph discusses the importance of assuring test accuracy in the testing process and raises a specific concern about direct access “as there is no assurance of the quality of the test result.” However, with regard to direct access, a major concern is that information purported to be health-related will be provided to persons in the absence of the necessary medical expertise important for its appropriate understanding and use (or that the test should have even been taken in the first place).

6.49 CLIA is now referred to as the Clinical Laboratory Improvement Amendments. The reference to the data can be dropped since there have been significant changes since. The second sentence should be clarified because American Board of Medical Genetics and American College of Medical Genetics have different purposes.

Also, in the United States, the Clinical Laboratory Improvement Amendments establishes quality standards for all clinical testing laboratories to ensure the accuracy, reliability, and timeliness of the test result. At this time, there are no specific requirements under CLIA that address genetic testing although there are efforts underway to augment the current regulations. In the United States, professionals directing genetic testing laboratories are qualified under a number of mechanisms. These mechanisms range, based on federal and depending upon State laws, from holding licensure as a doctor of medicine or osteopathy together with laboratory training or experience to achieving board certification (of which the

American Board of Medical Genetics and the Molecular Genetic Pathology subspecialty of the American Board of Pathology and ABMG are examples) to demonstrated previous specific experience as director of a clinical laboratory. Many laboratory directors are members of the American College of Medical Genetics or other relevant professional organizations. See [www.acmg.net](http://www.acmg.net) for more information.

### **Section C**

The discussion in this section recognizes that the use of genetic information will continue to increase in medical practice and urges that this information be considered as part of general medical information. U.S. practice does not require that genetic counseling be provided in all cases but rather that the degree of counselling be based on the risks associated with a particular test. This allows support resources to be directed to those who may need additional services due to the potential implications of the test results. With the increased use of genetic tests that are less predictive, the delivery of information to the patient will be less in the realm of traditional genetic counseling and more in the area of guidance from primary care providers. The document mandates non-directive genetic counseling for genetic tests. While this is appropriate for traditional genetics based on single gene disorders, such services will be impossible (and likely not appropriate) for wide-spread genomic applications in health care that are based on variation in one or multiple genes. In addition, counseling in these circumstances may be directive (e.g., avoidance of environmental exposures). Educational efforts for primary care providers who will be applying these tests in their practice are essential.

6.63 Some countries have established certification standards for genetic counseling. In the United States, the American Board of Genetic Counseling accredits training centers and certifies genetic counselors. See [www.abgc.net](http://www.abgc.net) for more information.

Dr Alvin Wong Seng Cheong M.B.B.S., M.R.C.P. (U.K.)
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26 May 2005

Members of the Bioethics Advisory Committee:

I thank you for the opportunity to have spoken at the meeting at the Sheraton Towers on Tuesday 17 May 2005. I was asked by the Catholic Medical Guild (CMG) to be part of their panel, and I had earlier submitted a short paper to them. In the course of the meeting and while listening to the other distinguished speakers, I realised that having come from a background of both clinical medicine and laboratory research I could contribute more specifically from a philosophical and bio-scientific viewpoint. It is important for those of us in positions of government to be conversant with both the *science of reasoning* as well as the *science of technology*.

As I had received many positive and kind comments after my presentation (from members of the panel as well as the different groups present, even from the secretary), I thought it would be opportune to collate those points on paper, with some additions.

A. When is the beginning of human life?

1. I started out by addressing a point raised by Chairman that the some religious groups had used differing time points: e.g. 4 months of pregnancy, 40 days of pregnancy etc, to guide what could or could not be done to the embryo or foetus. The 14-day rule itself, supposedly based on the beginnings of the nervous system in the embryo, is one such other definition of the beginning of life.
2. I questioned those present (without meaning to offend any party), whether it was possible to determine accurately those time points. Do we judge the decision on the licit-ness to terminate a pregnancy based on the woman's memory of her last menstrual period? Do we go by the ultrasound technique dependent on the operator's personal experience and skill? How arbitrary can it seem for us to say that it is licit to destroy the embryo today but not tomorrow, if the defined time point (40 days or 4 months) is supposedly at midnight tonight? How many days is one month supposed to have?
3. I had a letter published in the Straits Times a few years ago on the arbitrariness of the 14-day rule. We had surely come to know of the 'beginnings of the nervous system at 14 days' after some technological advancements gave us the ability to do so; before such a time in the history of medicine we did *not* have the means to know. So as science advances further might we not find the evidence that the beginnings of the nervous system are even earlier? That the incipient stages of the embryo's 'sensation' are already in motion? *Are we again going to change the*

*definition of life then?* Is it our technological abilities that determine when life begins? Will the avid proponents of the 14-day rule say something avidly against the definition for a ‘legal abortion’ at 24 weeks?

4. I underlined the fact that from human reasoning alone, from *philosophy*, one can form certain principles on the beginning of human life. I urge the BAC to understand the premise that we *do not even need to argue from the standpoint of faith*. The robustness of our ethical decision-making can be judged on *how scientific our reasoning process has been*.
5. In medical school I remember using the recommended textbook on embryology by Keith Moore. Medical students are told, right at the beginning of their arduous course: “Human development begins at fertilization when a male gamete or sperm (spermatozoon) unites with a female gamete or oocyte (ovum) to form a single cell—a zygote. *This highly specialized, totipotent cell marked the beginning of each of us as a unique individual*”<sup>1</sup> (emphasis added). It is without a doubt that human life, including yours and mine, begins at this point. *This is what the science of embryology tells us*.

#### B. But the culture of death has arrived!

1. March this year saw the publication of the Groningen protocol in the New England Journal of Medicine, which was about the euthanasia of severely ill newborns. As euthanasia was already part of the culture of the Netherlands, the article was even about a systematic way “to provide all the information needed for assessment and to prevent interrogations by police officers ... for cases in which a decision is made to actively end the life of a newborn”.<sup>2</sup>
2. *There is no real difference between the infanticide of the Dutch seen here, and what we do in PGD, PTT, or PND with a view to abortion*. It is the active termination of human life. It is also called murder. The culture of death desensitizes us to this fact. Murder is disguised as compassion, as reproductive choice, as medical advancement. The culture of death has arrived in a most insidious way.

#### C. What is good medicine?

1. In my training years in medical oncology, I remember being told one day by my consultant of a pregnant woman who was diagnosed with breast cancer. The first ‘therapy’ that he seemed to recommend was that of an abortion, which I of course disagreed with. Some years later, the University of Texas M.D. Anderson Cancer

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<sup>1</sup> Keith L. Moore and T.N.V. Persaud, *The Developing Human: Clinically Oriented Embryology*, 5<sup>th</sup> edition.

<sup>2</sup> *Eduard Verhagen, M.D., J.D., and Pieter J.J. Sauer, M.D., Ph.D.* The Groningen Protocol — Euthanasia in Severely Ill Newborns. *N Engl J Med*, March 10 2005, Volume 352:959-962.

Centre in Houston published a prospective clinical trial of chemotherapy administered to pregnant women with breast cancer from the 2<sup>nd</sup> trimester onwards, showing its feasibility and efficacy. I recently treated a 38-year old lady with high-risk (lymph node positive) breast cancer diagnosed while she was carrying her 3<sup>rd</sup> child. She had her mastectomy done in the 1<sup>st</sup> trimester, and adjuvant chemotherapy (consisting of cyclophosphamide, adriamycin and 5-fluorouracil) was commenced in the 2<sup>nd</sup> trimester. She completed 6 cycles of chemotherapy and has delivered a healthy baby 3 weeks ago. She is now preparing to undergo adjuvant radiotherapy.

2. If termination of pregnancy was seen as the answer to all medical problems that the expectant mother develops, we would have very little 'medical obstetrics' per se. Medicine is about finding solutions to medical problems, either for cure or control of disease, or for palliation. To extinguish the very lives we are supposed to be responsible for is *not* medicine at all.
3. I know that there are *probably* cases of abortion done every year for thalassemia. When I was in medical school I saw children with  $\beta$ -thalassemia major who were blood transfusion-dependant and had 'chipmunk-like facies'. Last week my paediatrician colleague told me that he had a *25-year old* patient with thalassemia major: "she has *no facies* ... she looks beautiful ... she has a boyfriend ...". I repeated to those of you present: "she has *no facies*...".
4. I quoted from a 1999 publication in the New England Journal:

The marked increase in survival, to the fifth decade of life, of patients with well-managed  $\beta$ -thalassemia in developed countries represents one of the most dramatic alterations in morbidity and mortality associated with a genetic disease in this century.<sup>3</sup>

And from a more recent one:

In the last decades, treatment of patients with beta-thalassemia has changed considerably, with advances in red cell transfusion and the introduction of iron chelation therapy. This progress has greatly increased the probability for a thalassaemic child to reach adult age with a good quality of life. At present, the prognosis for thalassemia major patients is "open-ended". Compliance with the conventional treatment and psychological support are critical to obtain good results. The expectancy of a long survival of good quality encourages the patients to plan their future life, having a job, a family and often children. Optimal treatment of thalassemia major is expensive and for this reason, unfortunately, available only for a minority of patients in the world. Despite the significant advances, other progresses are expected to further improve survival and quality of life. The major aim is the cure of the disease, increasing the possibility of bone marrow transplantation using HLA-matched unrelated donors, and hopefully, in the future, gene therapy. However, even the conventional treatment and in particular iron chelation is expected to improve. Efforts should be made by the Western countries, and by the international health and economic organizations to provide continuous and concrete support for achieving a high standard of management for thalassemia in all places of the world.<sup>4</sup>

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<sup>3</sup> Olivieri NF. The beta-thalassemyias. N Engl J Med. 1999 Jul 8. Vol 341(2):99-109.

<sup>4</sup> Galanello R. A thalassaemic child becomes adult. Rev Clin Exp Hematol. 2003 Mar;7(1):4-21.

5. Members of the BAC, *this* is medicine: when we develop over time, with biotechnological advancements, notwithstanding the arduous demanded, true and ethical solutions for the diseases that we face. Transfusion therapy and iron chelation techniques have been key factors in improved thalassemia treatment. Bone marrow transplantation is known to be even curative. I came across foreign<sup>5</sup> and local<sup>6</sup> authors trying to open up greater possibilities for the sources of hematopoietic stem cells using matched unrelated cord blood, perhaps a fortuitous resource provided by nature, just waiting to be tapped. The potential in this resource highlighted by these authors could thus be *the ethical alternative to PTT*.
6. I looked at the survival curves in thalassemia major and found this<sup>7</sup>:

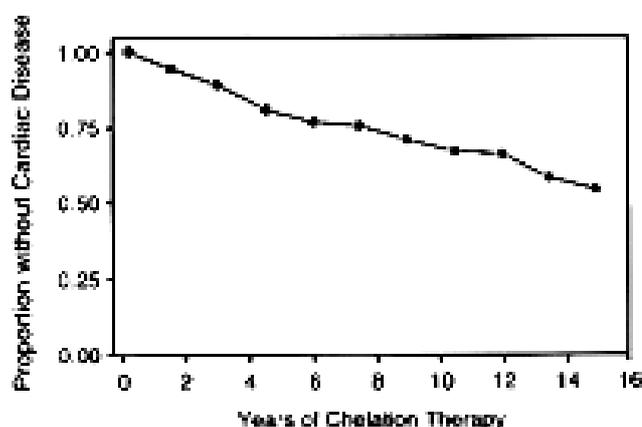


Figure 1. Survival without Cardiac Disease during Chelation Therapy in 97 Patients with Thalassemia Major.

This curve was obtained more than 10 years ago! What could it be like now?

7. In advanced cancer treatment, which I am more familiar with, history can be made by an average improvement in the median survival of 2 or 3 months. Both the pharmaceutical industry and the scientific community get excited over this magnitude of gain as long as it can be proved to be statistically significant. The

<sup>5</sup> Jaing TH, Hung IJ, Yang CP et al. Rapid and Complete Donor Chimerism after Unrelated Mismatched Cord Blood Transplantation in 5 Children with beta-Thalassemia Major. *Biol Blood Marrow Transplant.* 2005 May;11(5):349-53.

<sup>6</sup> Tan PL, Shek PC, Lim LC, et al. Umbilical cord blood stem cell from unrelated donors is a feasible alternate stem cell source for transplant in patients with genetic diseases. *Ann Acad Med Singapore.* 2004 Sep;33(5 Suppl):S82-3.

<sup>7</sup> Nancy F. Olivieri, David G. Nathan, James H. MacMillan, et al. Survival in Medically Treated Patients with Homozygous  $\beta$ -Thalassemia. *N Engl J Med*, 1994 Sep 1. Volume 331:574-578.

economic repercussions are tremendous. In thalassemia major we are talking in terms of *years and years of life*, which most advanced cancer patients are presently far from achieving ... Can we say we are practising *medicine* by doing PGD, PTT, or PND with a view to abortion for thalassemia? These techniques look more like *bad medicine*, or may I say, *not medicine* at all.

8. In another recent publication, it seemed that the threshold of cure for the terrible severe combined immunodeficiency had been broached<sup>8</sup>, although many safety<sup>9</sup> and ethical issues remain to be resolved. We live in exciting times where *good science* can achieve what was once thought impossible. The philosophy of PGD, PTT and PND with a view to abortion, run counter to this.
9. Mr Chairman, I remember urging you at the meeting, as an endocrinologist, to consider the success behind the screening and treatment of congenital hypothyroidism. What great medicine we have! Could we have seen this day if we chose instead to exterminate all cretins?
10. In no way do I mean to ridicule the aims of medical oncology in *advanced* cancer patients – far from it in fact. My colleagues in the department have recently returned from the American Society of Clinical Oncology (ASCO) annual meeting in the U.S. (together with thousands of others), where many important advances would have been presented.
11. We are in the age of *targeted therapy*. You may call these ‘smart bombs’ or ‘guided missiles’, which only destroy the target cancer cells but not others. I recently had a patient with advanced lung cancer on the verge of death. A few days after starting him on a drug called Gefitinib (Iressa®), he took off his oxygen tubes and went home without breathlessness. I reviewed him recently in the clinic and he was well. Interestingly, Asians could be more responsive to this drug, based on the incidence of certain mutations of the Epidermal Growth Factor Receptor, especially in lung cancers developing in non-smokers<sup>10,11</sup>. The manner and degree of clinical improvement and prolongation in survival of these patients is unprecedented. Imatinib (Glivec®) is another such drug used to great effect in not just one but several cancers: chronic myeloid leukaemia, gastro-intestinal stromal tumour (GIST) etc. Almost instantaneous ‘functional’ response has been documented on

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<sup>8</sup> Hacein-Bey-Abina S, Le Deist F, Carlier F, et al. Sustained correction of X-linked severe combined immunodeficiency by ex vivo gene therapy. *N Engl J Med*. 2002 Apr 18;346(16):1185-93.

<sup>9</sup> Hacein-Bey-Abina S, von Kalle C, Schmidt M, et al. A serious adverse event after successful gene therapy for X-linked severe combined immunodeficiency. *N Engl J Med*. 2003 Jan 16;348(3):255-6.

<sup>10</sup> Mitsudomi T, Kosaka T, Endoh H, et al. Mutations of the epidermal growth factor receptor gene predict prolonged survival after gefitinib treatment in patients with non-small-cell lung cancer with postoperative recurrence. *J Clin Oncol*. 2005 Apr 10;23(11):2513-20.

<sup>11</sup> Han SW, Kim TY, Hwang PG, et al. Predictive and prognostic impact of epidermal growth factor receptor mutation in non-small-cell lung cancer patients treated with gefitinib. *J Clin Oncol*. 2005 Apr 10;23(11):2493-501.

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positron emission tomography (PET) in GIST patients treated with Imatinib, supporting the ingenious molecular design of the drug targeting a specific receptor on the cancer cell, producing impressive clinical results in a tumour for which no treatment for inoperable cases was previously known<sup>12</sup>.

12. I say again, we are in the age of *targeted therapy*. *Designer medicine* if you will. Medicine designed to heal and not to kill. Let us not miss out on it.
13. I could go on since I am aware of the landmark advancements in the field of oncology and haematology: the use of platinum based chemotherapy in curing ovarian cancer, the use of all-trans retinoic acid (ATRA) in acute myeloid leukaemia (M3 subtype), the use of bone marrow transplantation in various haematological conditions, of which thalassemia has already mentioned, etc. Who is this man called Lance Armstrong, winner of 6 Tour de France championships, who was cured of testicular cancer, which had spread even to his brain?
14. Are we not excited about the possibilities of in-utero surgery to correct life-threatening congenital conditions? Our efforts to practise good medicine, great medicine, previously thought to be *impossible medicine*, are undermined by the very aims of PGD, PTT and PND with a view to abortion.
15. I have another colleague in the field of palliative medicine who trained in Australia. He is an expert in interventional palliative techniques such as intrathecal analgesia, where a catheter is inserted into the thecal space of the spinal canal and pain-relieving medicine infused directly into the central nervous system. He is looking to expand the use of this technique to many clinical situations. When we cannot cure or control a disease, the emphasis shifts to palliation. While we can only *sometimes* cure a disease and *often* are reduced to controlling it, "*to comfort always*" we must ... so I was taught by my teachers in medicine who, needless to say, are men of greater stature. The Groningen protocol is not a solution in the realm of medicine, neither is PGD, PTT, nor PND with a view to abortion. My colleagues in the field of palliative medicine tell me that this important branch of clinical medicine has not achieved formal accreditation status as a specialty yet. Why are we slow to recognize the efforts of those who have trained in the science (and art) of alleviating human suffering?
16. You may argue that all these latest medical treatments are expensive. Treating a thalassaemic child may seem to be a burden on resources. You probably know that the procedures being debated, especially PGD and PTT, are not simple nor cheap either. I mentioned the drug Imatinib (Glivec®) earlier for treatment of unresectable GIST. I have patients with this previously untreatable disease who are in remission thanks to the generosity of the Max Foundation, started by Pedro Rivarola in honour of his late son Maximiliano. This foundation funds Glivec®, which costs

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<sup>12</sup> Demetri GD, von Mehren M, Blanke CD, et al. Efficacy and safety of imatinib mesylate in advanced gastrointestinal stromal tumors. N Engl J Med. 2002 Aug 15;347(7):472-80.

thousand of dollars each month, for needy patients worldwide<sup>13</sup>. The founder, whose “vision, leadership and compassion have enabled The Max Foundation to assist countless sick persons across the globe”<sup>13</sup>, has since gone on to pursue other international opportunities related to cord blood research<sup>14</sup>. I recently had another patient with lymphoma who had her treatment (including Rituximab, a state-of-the-art monoclonal antibody) funded by the Leukemia and Lymphoma Foundation. The National Kidney Foundation, which has been supporting the life prolonging dialysis treatments of so many kidney failure patients in Singapore, has even announced its plan to fund cancer therapy<sup>15</sup>. It is obvious that the resources are out there waiting to be garnered. There will always be generous people who will endorse *good medicine* with their money, time and effort.

#### D. Motherhood versus manufacture

1. I recounted this incident for the benefit of the BAC. My female colleague who was pregnant with her 3<sup>rd</sup> child had severe nausea one day. She had come to work that day but looked as though she could not continue with her duties. When I offered to give her an anti-emetic to relieve her symptoms, she politely declined, saying: “nothing artificial ...”. I was impressed, and will remember what she said for a long time.
2. For this is motherhood. When a mother forgoes her own, even legitimate, comforts for the sake of the child she has conceived. The anti-emetic I had offered would be something that had been time-tried and proven safe in pregnancy. Yet this mother reacted with a maternal instinct so powerful that I had no answer. There are very few things more powerful than a mother’s love for her baby.
3. Members of the BAC, which mother never experienced *any* pain? Those of you with spouses and children, have you not experienced for yourselves that *sorrow is the touchstone of love*? And which child never experienced pain too? Another friend of mine has 4 children. I got to know that the 4<sup>th</sup> child has Down’s Syndrome. One day I heard the father speak about the joys that the other normal siblings would have when they played with their little brother. I know of another couple, whose own children had already grown up and married, who bravely adopted a Down’s child. After a stormy infancy, he is now “uncle” to his nephews and nieces, and so much a part of the family. I urge you not to underestimate the capacity of the human heart to love a sick child or any other sick family member. If we did not have this capacity we would not be human.
4. True parenthood is about sacrifice. Are we about to endorse a new era of *manufacture* instead of motherhood? PGD, PTT, and PND with a view to abortion

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<sup>13</sup> [www.themaxfoundation.org](http://www.themaxfoundation.org)

<sup>14</sup> <http://www.themaxfoundation.org/News/News.aspx?trgt=newsfullstory&storyid=68&lang=engl>

<sup>15</sup> <http://www.nkfs.org/events.htm>

are totally contradictory to the essence of parenthood, which is about self-giving, not selfishness.

E. The right to object is an objective right

1. It goes without saying, that conscientious objectors to abortion should be protected by law. I have witnessed a fellow houseman (and have heard of others), who did not ask to work in obstetrics and gynaecology, stand firm in his refusal to *cooperate* in the evil of abortion and the like. This houseman was told by his superiors of the possibility of having his posting disqualified. Could the law have protected him?
2. As health administrators and healthcare workers, our rights in conscientious objection should be protected. This should apply *in any act that may result in the evil of abortion*, including something like the notification of thalassemia carriers to the National Thalassemia Registry. I encouraged Professor Kaan to take up the issue of making legal requirements for such notification forms to include clauses that protect the consciences of the physicians concerned, since notification may also be done for ethical reasons. I have also advised the CMG to specifically mention this in their submission, and included an example as to how this clause might be phrased.
3. Let us not assume that everyone agrees with everything permitted by civil law. When I attended the recent launch of former Member of Parliament Joseph Conceicao's memoirs, the guest-of-honour, DPM Jayakumar talked about how Mr Conceicao had previously raised objection to the Abortion Bill in parliament<sup>16</sup>. I took this as a commendation of someone who dared to stand up for his principles.

F. In conclusion

1. At our meeting, in response to what Chairman had alluded to regarding arguments based on faith, I reminded the BAC of what Hippocrates, in the *pre-Christian* era, swore in his famous oath:

I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art...

2. I encourage members of the BAC to re-live a little the times of the ancient Greek thinkers such as Aristotle, whose conclusions and methods, though perhaps not perfect, give us an insight into what must unite humanity when judging its behaviour – a common *natural law*. I am talking about *a moral law inscribed in the hearts of men*, inherent in and based on his very human nature, which is above that of a purely animal nature. This human nature has to be the same for all of us, or else

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<sup>16</sup> “As an MP he spoke his mind on the issues, and when the Whip was lifted, he voted against the Abortion Bill.” Remarks by DPM Jayakumar on the occasion of the launch of Mr Joe Conceicao's book. Press releases: 24/09/2004. <http://www.mfa.gov.sg/internet/>

we are admitting that humanity is a race composed of different species. In this common natural law the need to be *absolute* in matters essential to the human nature (issues of life and death, sexuality) becomes obvious. *Moral relativism, by definition, cannot sustain itself, since it is a self-defeating principle.*

3. I hope I have inspired the BAC to take on the challenge to find the ethical solutions. The future is in our hands! The ethical solution to every problem can only be within the reach of our ingenuity and creativity. My colleagues at the National University Hospital were studying how bone marrow stem cells taken from the chest bone at a cardiac bypass operation can improve cardiac function after being injected into the damaged heart. When the surgeon splits open the chest bone en route to accessing the heart, the bone marrow containing stem cells are already there, staring at him in the face<sup>17</sup>. Often times the providential solution could be right “under our noses”<sup>18</sup>. Exciting and unprecedented developments take place as we speak<sup>19</sup>.
4. Lastly, I did encourage the BAC to peruse parts of “Beyond Therapy: Biotechnology and the Pursuit of Perfection” from the U.S. President’s Council on Bioethics (October 2003)<sup>20</sup>. Chapter 2 of this document “Better Children” for example, gives some insights into the dangerous ramifications of implementing PGD, PTT and PND with a view to abortion, ramifications of which I’m sure the Committee is already aware to some degree. As a known phenomenon, the pendulum of nature could well strike back with emphatic reproach for our mistakes.

Dr Alvin Wong Seng Cheong  
M.B.B.S., M.R.C.P. (U.K.)  
Consultant  
Dept of Haematology Oncology  
National University Hospital

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<sup>17</sup> <http://wired-vig.wired.com/news/print/0,1294,44671,00.html>

<sup>18</sup> Murrell W, Feron F, Wetzig A, et al. Multipotent stem cells from adult olfactory mucosa. *Dev Dyn*. 2005 Jun;233(2):496-515.

<sup>19</sup> Escolar ML, Poe MD, Provenzale JM, et al. Transplantation of umbilical-cord blood in babies with infantile Krabbe's disease. *N Engl J Med*. 2005 May 19;352(20):2069-81.

<sup>20</sup> <http://www.bioethics.gov/reports/beyondtherapy/index.html>

From: Dr Peter Ang  
Consultant  
Department of Medical Oncology  
National Cancer Centre

Received by email: 10 May 2005

“This is my feedback to the BAC.

I would like to add my views to the recommendation of the BAC on:  
“Ethical, Legal and Social Issues in Genetic Testing and Genetics Research”

Specifically, with respect to the following: “Recommendation 18: Susceptibility testing should not be applied clinically unless there is unequivocal empirical evidence of validity and utility.”

The field of susceptibility testing is evolving rapidly since the sequencing of the genome. As we understand more of the genes involved in cancer, more information regarding risk reduction or prevention is becoming available. Most of these highly penetrant cancer genes are not common and it is difficult for clinical trials or studies to truly provide “unequivocal empirical evidence” for it to be useful. Nonetheless, there is emerging data albeit slowly emerging through studies done in such families and some may be less than perfect data. I do agree that frivolous genetic testing without adequate information and counselling is not useful or even be harmful.

Please reconsider the wording of the recommendation.”

From: Aviva Ltd
Received by email: 17 May 2005

“Thank you for inviting comments on the consultation paper on the Ethical, Legal and Social Issues in Genetic Testing and Genetics Research. The paper was circulated via the Life Insurance Association of Singapore, and Aviva Ltd, being one of its members, is happy to be able to express our views.

As mentioned by Mr John Lockyer in his letter to you and his attached paper, a contract of utmost good faith with an obligation on each party to disclose relevant information. We feel very strongly about this. An insurance applicant’s knowledge of his or her mortality or morbidity would undoubtedly be classified as material information, because the non-disclosure of such information goes against this core principle of insurance, and would greatly prejudice an insurer. Consequently, such inequality of information would lead to the risk of anti-selection to the detriment of insurers and the insurance industry. This moral hazard is further accentuated by the fact that clinical genetic testing has a far greater predictive value than any current medical examination or investigation to determine to a significantly higher degree of probability a person's mortality and morbidity.

Therefore, though we appreciate the ethical and social issues surrounding the disclosure of genetic testing information, we strongly feel that the law must not bar any insurer from obtaining such information if a free and informed consent is given by the applicant. The treatment of disclosure of information must accordingly be regarded as any other medical information currently available and all provisions of confidentiality and privacy equally applied.

One other view that we would like to present with regards to non-disclosure of genetic testing information is that at the present moment, genetic testing is a very deliberate and expensive procedure. It can therefore be inferred that such testing would have been done with the full knowledge and conscious consent of the subject. Except under conditions of research where the subject can opt not to know the results of the testing, the proposed framework stipulates that the results must be communicated without undue delay to the subject. This strongly suggests that any non-disclosure of knowledge of results can only be fraudulent and the insurer would therefore be entitled to handle the matter as it would any instance of fraudulent non-disclosure.

In conclusion, we support the efforts of BAC to establish clear policies and framework on genetic testing. We urge that any policies will not impede the conduct of life insurance business in Singapore, and feel that with the existing infrastructure of handling private and confidential medical information, with some refinements, could sufficiently address concerns raised in the consultation paper.”

From:	Chief Actuary's Office Great Eastern Life Assurance Co Ltd
Received by email:	12 May 2005

“Our only comment is as follows:-

*‘Recommendation 7: Genetic test results should not be disclosed to third parties, including employers and insurers, without the free and informed consent of the individual.’*

Agree. If an applicant's attending doctor indicates that a genetic test has been done, insurance companies should be able to see the results. Insurers need to have access to all information applicants have, in order to avoid anti-selection since applicants might use their own genetic information to obtain the highest and most comprehensive insurance coverage.

However, insurers should be prohibited from requiring that new tests to be performed to secure coverage.

Insurers should also educate the public that disclosing results of genetic tests done does not necessary mean that their coverage will be declined. Insurers should also ensure that their underwriters have the adequate knowledge on genetic conditions so that they will not decline coverage because it is a rare condition.”

From: Mr Seah Seng Choon  
Executive Director  
Consumers Association of Singapore

Received by email: 31 May 2005

“General comments

We agree that all precautions should be taken to ensure that parties involved in such testing are clear of their roles and obligations. We are concerned that there is no explicit mention of measures that will be put in place to deter breaches of the rules suggested in your recommendations although you have alluded to some possible action such as ensuring the parties work "within legal and ethical limits". We feel that it may be better to be explicit about the matter in order to ensure compliance.

On Recommendation 7, two operative words are noted:-

- a) "should not be disclosed" - as opposed to 'shall not' which is stronger. This opens up the possibility that there may be circumstances that the testing agency can disclose without the consent of the individual.
- b) "without the free and informed consent of the individual" - This is easily circumvented as follows. The testing agency itself may not disclose the information to the insurer or third party, however, the individual himself may be obliged render full co-operation to the insurer or third party have the data disclosed. Under insurance law, the insured has a duty to disclose all material facts, in this case, the test results known or obtained, at the time the proposal for insurance is being made to the insurance company. If the insurer has knowledge that the insured had participated in such a test, it is quite likely that if the insured refuses to give his consent for the data to be released that (1) the insurer may refuse to pay for the insured failure to disclose material facts and/or (2) if the insured sues the insurer, for the insurer to obtain a court order for the data to be disclosed. Of course, it may be possible for the insured's solicitors to argue that the insurer is trying to 'fish' for info and does not have any basis for saying that the data is relevant but we think it is unlikely that such an argument in this instance would be successful.”

**From:** "Dean-Biological Sciences" <D-SBS@ntu.edu.sg>  
**To:** <contactus@bioethics-singapore.org>  
**Sent:** Tuesday, May 17, 2005 5:36 PM  
**Subject:** Feedback on Consultation Paper

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**Nanyang**  
Technological University

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17 May 2005

Associate Professor Terry Kaan  
Chairman, Human Genetics Subcommittee  
Bioethics Advisory Committee  
20 Biopolis Way  
#08-01 Centros  
Singapore (65) 64789581

Dear A/Prof Kaan

**FEEDBACK ON CONSULTATION PAPER**

We refer to the 'ethical, legal and social issues in genetic testing and genetics research' consultation paper, and our comments are as follows:

- 1) Should probably encourage to implement part 4.12 "Involuntary Genetic Testing" according to UK legislation ASAP.
- 2) With regards to recommendation 24, genetic counselling should be conducted by certified genetic counsellors. To implement this regulation, the Singapore Board of Genetic Counselling has to be established to prepare and administer examinations to certify individuals who provide services in the genetic counselling. Please see [<http://www.abgc.net/genetics/abgc/abgcmenu.shtml>].

Thank you.

Yours sincerely,

James Tam  
Professor and Dean