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16 May 2005

Associate Professor Terry Kaan
Chairman
Human Genetics Subcommittee
Bioethics Advisory Committee
20 Biopolis Way, #08-01 Centros
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BY FAX & POST

Fax: 6478 9581

Dear Prof Kaan

REQUEST FOR FEEDBACK ON CONSULTATION PAPER:
ETHICAL, LEGAL AND SOCIAL ISSUES IN GENETIC TESTING AND GENETICS RESEARCH

1. I refer to your letter of 4 April 2005 to Dr Yuen Kwong Wing, Chairman, Clinical Board, National Dental Centre, requesting for feedback on the above consultation paper. I have been asked to provide my comments.

2. The paper is comprehensive and well-written, though I propose some modifications. They are as follows:

A) Pg 9 – Section on "Free and Informed Consent: Freedom of Consent and the Right to Information"
Under 3.7: We propose that information to be provided to individuals before any Genetic Testing should include:

(e) implications (including social, ***economic and legal*** risks) of the test result (negative and positive) for the individual and his or her family. ***The possible need for disclosure to third parties such as insurers and employers must be highlighted. Patients must be informed that failure to disclose a genetic information disorder/condition at the time of application for insurance cover may render the insurance legally ineffective.***

(i) that the confidentiality of the test result would be maintained ***except in special circumstances e.g.***

i. ***when there is a high probability both that harm will occur to identifiable individuals or the society at large if the information is***

withheld and that the disclosed information may actually be used to avert harm.

ii. ***when the harm that identifiable individuals (if any) would suffer would be serious.***

I am well aware that these points have been addressed under the section of "Genetic Counselling: Pre-test Genetic Counselling" on Pg 34, 6.58. But as the paper has rightly stated that the physician taking consent for the genetic test may not be the same offering genetic counselling, it is thus imperative that these points be reiterated in the section on "Free and Informed Consent". It is also better that these points be stated in the Patient Information and Consent Form as these carry the most important and pertinent implications to the patient apart from the psychological/emotional burden to the patient and his genetic relatives. If I am a patient, I will certainly want to know these and weigh these against the benefits of genetic testing. When the test is undertaken will also become a consideration.

B) Pg 18 – Section on "Direct Supply of Genetic Testing to the Public": -
Under 4.11 Last Line: For a similar reason, the advertising of direct genetic tests to the public should be strongly discouraged.

I am of the opinion that this is open to interpretation, and is not legally binding. Since your committee has recommended that Clinical Genetic Testing should be confined to a healthcare context (Recommendation 1) and discourages free public access to Genetic Testing, would it not be more appropriate to "prohibit advertising of direct genetic tests to the public", particularly by medical laboratories. This should be differentiated from Patient Information Pamphlets/ Notices versus advertising to "sell a product/service".

3. Except for a typo error on Pg 23, 6.14, Line 1 – "***practiced***" should be replaced by "***practised***" - I congratulate you and your committee on a job well done.

Yours sincerely

DR TEH LUAN YOOK
CHAIRMAN
NDC INSTITUTIONAL BOARD REVIEW

Cc Dr Kwa Chong Teck, Executive Director, NDC
Dr Yuen Kwong Wing, Clinical Advisor, NDC

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10 May 2005

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Dear A/Prof Kaan

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

Thank you for your letter of 4 April 2005.

As requested, please find enclosed feedback from Dr Hwang Nian Chih, Acting Head, Cardiac Anaesthesia, National Heart Centre.

Thank you.

Yours sincerely

A/Prof Koh Tian Hai
Medical Director, National Heart Centre

A:bac – feedback 100505

3.21 In cases of dependent relationships, it is important to ensure that consent is both informed and freely given. The Nuffield Council on Bioethics stated that special care is necessary when seeking consent from prisoners, student volunteers and individuals who do not speak English.[15] Similarly, it would be unacceptable for those in positions of power to engage in actions that either coerce individuals into taking genetic tests or inhibit individuals from taking the same for fear of social or economic disadvantage as stated by the Human Genetics Society of Australasia.[16] We agree with these statements. Where there are reasons to believe that a person agrees to Genetic Testing for fear of losing healthcare benefits, this misconception should be corrected. One way to do this is to expressly indicate when obtaining consent that however a person decides, any healthcare, employment, welfare, or other benefits that are currently provided or in prospect, will not be jeopardised.

Recommendation 6: Genetic Testing involving vulnerable persons should be conducted only if appropriate free and informed consent has been obtained. In the case of persons in special relationships, extra care should be taken to ensure that the consent is freely given. Clinical Genetic Testing should only be conducted if it is medically beneficial. Genetic Testing for research should only be conducted if the research is considered of sufficient importance and there is no appropriate alternative test population.

Confidentiality and Privacy

3.22 Healthcare professionals and researchers involved in Genetic Testing have an obligation to protect the confidentiality of Genetic Information. We note Article 7 of the 1997 *Universal Declaration on the Human Genome and Human Rights* of the United Nations Educational, Scientific and Cultural Organisation (UNESCO), which states: "Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law." The WHO has similarly stated: "Genetic data should only be used to advantage and empower an individual or family, and for better treatment or prevention of disease. Data relevant to health care should be collected and kept by medical geneticists in secure confidential files."[17] We agree with these statements and we are of the view that genetic test results should not be disclosed to third parties, including insurers and employers, without the free and informed consent of the individual.

3.23 Individuals should be provided information on how their privacy will be protected, before they consent to Genetic Testing. We agree with the HGC's position that Genetic Information should generally not be obtained, held or communicated without the free and informed consent of the individual.[18] Certain individuals may be unwilling to share or divulge their Genetic Information to their family members, other healthcare professionals or researchers. Hence, healthcare professionals and researchers should exercise special care in protecting the individual's privacy and the confidentiality of such information. However, we reiterate our view that the ethical principle of privacy and confidentiality is not an absolute right in itself. There may be

15 Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (1993), paragraph 4.27.
16 Human Genetics Society of Australasia, *Predictive Genetic Testing and Insurance* (1999).
17 WHO, *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetics Services* (1998), Executive Summary.
18 HGC, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (2002), at page 42.

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ROC No. 200104750M

16 May 2005

The Secretariat
Bioethics Advisory Committee
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Dear Sir,

Consultation paper feedback on "Ethical, Legal and Social Issues in Genetic Testing and Genetics Research"

Thank you for allowing the National Kidney Foundation Singapore an opportunity to provide feedback on the consultation paper: "Ethical, Legal and Social Issues in Genetic Testing and Genetics Research".

We feel that this consultation paper represents an extremely important move in the right direction, given the context of an increasing amount of biomedical research being carried out in Singapore.

After thorough reading and examination of this paper, we have the following comments to offer:

1) In **Recommendation 3**, 'consent should also be obtained for future clinical and/ or research use of tissue specimens' - This has implications for many of the current research practices being carried out in our healthcare institutions. Currently, blood and tissue samples being collected for routine investigational purposes are not subject to the consent process. It is assumed that if the data is de-identified and retrospective in nature, it may be suitable for usage. Our view is that de-identified data should fall under this category also and that consent should thus be sought. It would be useful if the council could provide a template for consent for future, hitherto unknown research purposes to be used at the point of tissue collection.

2) In **Recommendation 15**, reference is made to 'serious genetic diseases'. We submit that the definition of serious genetic diseases should be made clear and a list of such diseases provided as an annex to the recommendations.

3) In **Recommendation 21** on the qualifications of personnel who can interpret genetic tests - 'Healthcare professionals who are appropriately qualified or have sufficient experience'. We feel that this statement is insufficient and too vague as a safeguard to ensure that only a select group of healthcare professionals have ready access to genetic tests. Perhaps a register of such professionals should be established at least initially and the guidelines gradually relaxed. This should prevent unnecessary abuse of confidential data. Previous similar exemplary safeguards can be drawn from the pharmaceutical industry - when Viagra was first introduced, only endocrinologists and urologists were allowed to prescribe and once the safety was well established, this was expanded to all practitioners.

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4) Lastly, may we also recommend the inclusion of a broad clause allowing non-consented use of tissue/ blood samples in times of national emergencies i.e. for identification of subjects during mass casualty events.

We hope that our comments were constructive and of use to the committee. Once again, please accept our appreciation for the opportunity to provide feedback on an issue that is of prime importance in our drive to be a premier biomedical research hub.

Thank you

Yours sincerely,

Dr Benjamin Chua
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Associate Director
Clinical Research Office
Medical Affairs and Planning
NKF Singapore

Dr Jeremy Lim
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Head, Medical Affairs and Planning
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NMEC's input to BAC's Consultation Paper on "Ethical, Legal and Social Issues in Genetic Testing and Genetics Research"

1 General Ethical Considerations

1.1 With regards to Para 3.3 stating that "If there is a possibility for sample taken for clinical purposes which may be used for research in future, this must be made known to the patient….", NMEC proposes that this be made known to the patient in writing.

1.2 With regards to Para 3.9(e) stating that "participants in genetic testing for research should be provided with information regarding the confidentiality of records identifying the tested individuals. NMEC suggests that the clause "subject to the regulation of discovery of medical information in Singapore" be added.

2 Recommendation 1 (Genetic Information Derived from Clinical Genetic Testing should be confined to a healthcare context, owing to its complex nature and the need for professional input. Accordingly, it should be regarded as medical information and the highest ethical standard should be applied in its derivation, management and use)

2.1 NMEC proposes to add that the approval for genetic testing/ trial should be sought from the Institutional Review Board (IRB)/Institutional Ethics Committee (which reviews and monitors all research work with special attention to the requirements for free and informed consent and medical confidentiality).

2.2 NMEC proposes that BAC defines what the "highest ethical standards" for medical and genetic information's management and use will be, as medical records are actually discoverable.

3 Recommendation 3 (Genetic Testing should be voluntary and conducted only after free and informed consent has been obtained. Consent must be based on sufficient information, which includes the nature, purpose, risks and implications of the test. Consent should also be obtained for future clinical and/or research use of tissue specimens)

3.1 NMEC suggests that re-consent (signed) is necessary for a change in purpose for the use of the genetic information. If this is not possible, re-approval from the IRB should be sought.

3.2 In Para 3.9(g), in the context of research involving genetic testing, while it is agreed that subjects should be told they can withdraw from the research at any

time, it is generally felt that subjects should also be told what the withdrawal means. Most subjects being laypersons, would imagine that their withdrawal would mean not only their sample is destroyed but also the genetic information already derived from the sample would be destroyed. But this may not always be the case. On the contrary, the information is often de-identified and retained. If the researcher is willing to remove all patient identifiers and make the information subsequently untraceable, can the researcher keep the information even after the subject withdraws his consent? The implications of a withdrawal from the research should be properly explained to the subjects.

3.3 NMEC suggests that the report clarifies whether tissue typing performed to detect the HLA typing of an individual is considered as genetic testing.

4 <u>Recommendation 4</u> (An individual should be informed of the test result without undue delay unless he or she has indicated the wish not to know. However, the test result of newborn babies and children for treatable conditions should be disclosed. In research involving genetic testing, researchers should inform the individual prior to participation in the research whether the genetic information so derived will be disclosed from him or her)

4.1 NMEC proposes that the researchers should also inform the subject the following information:

- For how long the specimen will be kept, and when it will be destroyed;
- That he may request for the specimen to be withdrawn from storage and destroyed at any time;
- That confidentiality will be maximized by double-coding; one code for the sample and another for the DNA; and
- That genetic information if released could potentially be misused and affect his employability and insurability.

4.2 In Para 3.10, there should not be an issue as to the individual refusing to disclose a test result that may be medically beneficial to a third party. Individual rights take precedence and free and informed consent from the individual should still be obtained.

4.3 With regards to Para 3.11 stating that "...a healthcare professional may decide to postpone disclosure of the test result if the individual is not in a suitable condition to receive such information. This may arise when the test result reveals a condition that cannot be medically treated or alleviated", it is generally understood that sometimes the disclosure should be deferred if the patient is too ill to receive the information at the time, However, it is not clear why this should be the case when the test results reveals a condition that cannot be medically treated or alleviated, or whether it should also apply if the patient is well, but just that the information relates to a condition that cannot be medically treated or alleviated.

4.4 Hence, it is proposed that so long as the genetic counseling prior to the test is performed correctly, the possibility of the information revealing such a untreatable condition should already be told to the patient and if he has agreed he wants to know, it is not for the doctor to exercise therapeutic privilege to withhold the information anyway. Therefore, the report should clarify if it means to refer only to a deferment of the disclosure or whether it is suggesting that doctors should have a right not to disclose the information at all so long as the test result reveals a condition that cannot be medically treated or alleviated, if they feel that the person would be unwilling to accept the information. There are problems if the patient is not informed even if the concern is based on a therapeutic privilege - this is because conditions that cannot be medically treated or alleviated at the present time may not always be so in the future, and if doctors wishes to withhold the information, are they going to be responsible to keep track of the information so that the information can be disclosed at a subsequent time when treatments for the condition become available? That would be a terrible burden for doctors to bear. It would be best to do a proper job of **pre-genetic testing counselling** to ensure the person is ready to receive the information, then disclose it when available

5 Recommendation 5 (We do not recommend the broad use of Genetic Testing on children and adolescents. Confirmatory Testing and Predictive Testing for genetic conditions where preventive intervention or treatment is available and beneficial in childhood are recommended. Carrier Testing should generally be deferred till the child is mature or when required to make reproductive decisions. Predictive Testing should generally be deferred where there is no preventive intervention or treatment, or where intervention or treatment is only available and beneficial during adulthood. However, in exceptional circumstances, parents and the physician should have the discretion to decide regarding Carrier and Predictive Testing, and genetic counselling should be an intrinsic part of the testing process)

5.1 NMEC proposes to insert the definition of "Predictive Testing" for genetic condition as its scope changes with technology. It can be defined as testing that:

- Improves life based on results.
- Provides information helpful for prescribing drugs.
- Suggests ways to avoid disease that one may be predisposed to.
- Predicts drug reactions.

5.2 In Para 3.14, it is stated that "when considering whether the child or adolescent's best interest is met by genetic testing, it should be considered in the context of the family". NMEC recommends deleting this statement and substituting that the context should in the interest of the minors only and the minor should not be tested in the family's interest.

5.3 In Para 3.16, it is recommended to include psychological assessment to determine the capacity of the child or adolescent to participate in consent-taking process.

6 <u>Recommendation 6</u> (Genetic Testing involving vulnerable persons should be conducted only if appropriate free and informed consent has been obtained. In the case of persons in special relationships, extra care should be taken to ensure that the consent is freely given. Clinical Genetic Testing should only be conducted if it is medically beneficial. Genetic Testing for research should only be conducted if the research is considered of sufficient importance and there is no appropriate alternative test population)

6.1 NMEC recommends that the report clarifies "vulnerable" persons who do not have the capacity to give consent like the mentally ill or impaired. It should also be useful to elaborate what the term "medically beneficial" to whom / the person having the test done.

6.2 In Para 3.19, the report recommends that "genetic testing for the mentally impaired should only be allowed with the consent of a person legally authorised to decide on his or her behalf". It is not clear if this is meant to apply only to Genetic Testing for research, or to Genetic Testing in general. Para 3.18 seems to differentiate between the two but in the final statement in 3.19, it just refers to "Genetic Testing". Therefore, whether the need for a court order appointing a Committee of the Estate or Person and consent from that person should be a strict requirement also for Clinical Genetic Testing when it is in the best interests of the mentally impaired person? Or when will it be imperative to diagnose the existence of genetic disease in family members? Right now, doctors can decide to carry out treatment in the best interests of a patient who is unable to give consent and when there is no one authorised to consent on his behalf. Is the requirement of consent from a court ordered legal guardian going to impose new requirements to be fulfilled if genetic testing is to be allowed?

6.3 In Para 3.20, it is proposed that the NS men and those serving in the military should also be considered to be persons in relationships of dependence. This is particularly so since their employer is the government whose access to information may be far greater than your typical employer. What if the military wants the genetic information of a soldier to be put into a dossier on the individual? Would they be allowed to call for the information?

7 <u>Recommendation 7</u> (Genetic test results should not be disclosed to third parties, including employers and insurers, without the free and informed consent of the individual)

7.1 NMEC agrees with the recommendation in Para 3.22 that "genetic test results should not be disclosed to 3rd parties, including insurers and employers, without the free and informed consent of the individuals". However, this is in conflict

with statements in Para 3.10 and Para 3.23 that the ethical principle of privacy and confidentiality is not an absolute right in itself. This statement also contradicts our current legislation on discovery of medical information in Singapore.

7.2 In Para 3.24, while the report provides some guidance in this area of when a doctor can disclose in breach of the duty of confidentiality, it is strongly recommended that this area be covered by legislation much like we see for HIV/AIDS disclosure in the Infectious Diseases Act, so that doctors are properly protected and there is greater clarity of when the exceptions apply.

8 <u>Recommendation 8</u> (Genetic Testing should be conducted through the intermediation of a qualified healthcare professional. Accordingly, the advertising of genetic tests by manufacturers or suppliers to the public is strongly discouraged. A comprehensive regulatory framework should be established for access to Genetic Testing services. Genetic tests that provide predictive health information should not be directly offered to the public)

8.1 NMEC proposes to add that advertising is strongly discouraged and should be regulated by the Ministry of Health or designated bodies. A regulatory framework is needed as soon as possible.

8.2 In Para 4.10, it was suggested that a comprehensive regulatory framework be established – however, such regulatory bodies will not have jurisdiction over internet or alternative suppliers. Eventually, there may be propositions to suggest that our tight regulatory framework may impede our progress for genetic testing, falling behind our neighbours for such services. Therefore, it is proposed that cooperation with other countries would be needed – probably within ASEAN.

9 <u>Section V on "Special Ethical Considerations for Human Genetics Research"</u>

9.1 NMEC proposes that in Para 5.6(e), there is a need to elaborate the 14 day rules for the embryos – i.e. notochord development etc.

10 <u>Recommendation 10</u> (Pre-implantation genetic diagnosis is permissible provided that it is subject to control by a relevant authority and limited to serious medical conditions. The relevant authority should license, monitor and assess preimplantation genetic diagnosis to ensure that it is employed within legal and ethical limits)

10.1 NMEC recommends that approval by the IRB is required for the clinical use of PGD as it is still regarded as experimental. A Registry of non-infertile couples undergoing the procedure should be established to review the short- and long-term outcomes of the parents and children.

10.2 In Para 6.15, NMEC proposes that it should be explicitly highlighted what "serious medical conditions" mean and constitute.

11 <u>Recommendation 11</u> (Use of preimplantation genetic diagnosis for sex selection and the selection of certain desired traits for non-medical reasons should be prohibited)

11.1 It should be added that PGD may be viewed as a technology by which cloning may be performed. Therefore, the report should clearly differentiate between these 2 terms.

12 <u>Recommendation 12</u> (Preimplantation tissue typing, whether as the sole objective or in conjunction with preimplantation genetic diagnosis to avoid a serious genetic disorder, is permissible but should be licensed and evaluated on a case-by-case basis)

12.1 NMEC proposes that an appropriate body or agency (e.g. licensing authority or hospital ethics committee) should be named in the report to issue licenses and evaluate the cases for PTT and PGD. Lay participation should be included within these agencies. There should also be an appeal mechanism included in cases of disagreements or disputes with this agency's views. In addition, if PTT for non-medical reasons are not allowed, BAC should address whether Singaporeans could go overseas for PTT and will this child then be registered as a Singaporean.

12.2 In the UK, there is a specific authority licensing any unit that proposes to carry out PGD. It looks at various points, including the reliability of the centre (it is quite difficult technically), the risk to benefits ratio of the specific disease tested for - compared to other methods (and will look at specificity and sensitivity issues), the availability of genetic counselling before and after the testing, etc. The license is site and disease specific.

13 <u>Recommendation 14</u> (Prenatal genetic diagnosis should be voluntary, conducted with informed consent and with appropriate pre- and post-test counselling. The prospective parents' choice of whether a genetic disorder warrants a prenatal genetic diagnosis or termination of the pregnancy should be respected)

13.1 NMEC wishes to clarify whether this recommendation would mean that prospective parents have full autonomy to decide on PGD and PTT or only on termination of pregnancy.

13.2 With reference to Para 6.27(c), NMEC proposes to substitute "at 12 and 22 weeks" to "<u>between</u>…".

13.3 In Para 6.31, it is right to state that it is unacceptable to use PND for the selection of any physical, social or psychological characteristics or normal physical variations. However when it pertains to a late-onset diseases in a foetus, this may be a slippery slope. BAC is recommending that PND be limited to serious genetic diseases. But what if it is albeit a serious disease, and the genetic testing can only show a slightly higher susceptibility to developing this late onset disease? Or what if it is serious, but a treatable condition? Can parents still decide to insist on PND because if the foetus can be potentially affected, they would want to have an abortion as they would rather try to conceive a "healthier" child the next time round? The guidelines on PND may have to be more specific if we do not want a slippery slope towards a form of prenatal selection using abortion.

14 Recommendation 16 (The appropriate professional bodies should prescribe detailed ethical guidelines on the practice of prenatal genetic diagnosis for their members)

14.1 If the professionals are the “guardians” of the Ethical guidelines, the report should also propose a separate central licensing authority that is able to overrule the Professional body if need be.

15 Recommendation 17 (Presymptomatic testing should be available for adults at risk who request it, even in the absence of treatment, after proper counselling and informed consent)

15.1 NMEC proposes to state that presymptomatic testing should be restricted to be performed by medical professionals only.

16 Recommendation 21 (Interpretation of genetic test results should only be performed by healthcare professionals who are appropriately qualified or have sufficient experience. Genetic counselling should immediately follow the disclosure of the test result, particularly if the test result is not favourable)

16.1 NMEC recommends that all healthcare professionals providing self-directed genetic testing should employ the services of trained/approved geneticists.

17 Additional Comment

17.1 It seems extraordinarily restrictive for paediatricians managing patients with potential genetic problems. For example, a child with beta major could have the diagnosis clearly made on blood films, FBC and Hb electrophoresis. Management of future pregnancies for the parents is vital. Genetic tests should not be restrictive in such circumstances.

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4 May 2005

Associate Professor Terry Kaan
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Dear Prof Kaan

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

Thank you and your committee for producing this very well written consultation paper.

I have read the paper and also sought comments from relevant colleagues in the NSC. We generally agree with the recommendations contained in the paper.

Other comments are:

1) How feasible is it to monitor and police laboratories offering genetic testing from overseas or via the Internet?

2) In view of the fact that there are numerous genetic tests and a long list of genetic illnesses, is it better to concentrate on conditions that are severe or have significant ethical, legal and social impacts?

3) What would be the advice for doctors who advise genetic testing in children whose parents adamantly refuse such testing, and such testing will be of benefit?

4) What would the advice be for matured children wanting to be tested but parents refusing such testing?

5) Would the archiving of specimens obtained for genetic testing be allowed and under what conditions?

Yours sincerely

A/Prof Roy Chan
Director

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20 May 2005

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Dear Terry

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

I refer to your Request for Feedback on Consultation Paper entitled " Ethical. Legal and Social Issues in Genetic Testing and Genetic Research". I am pleased to inform you that the feedback from our clinicians have been very favourable and agree with the 24 recommendations.

For your perusal.

Dr Tay Eng Hseon
President

Office of Life Sciences

NUS National University of Singapore

May 30, 2005

Associate Professor Terry Kaan
Chairman
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Bioethics Advisory Committee
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Dear Terry,

REQUEST FOR FEEDBACK ON CONSULATATION PAPER

Thank you for the opportunity to comment on the consultation paper entitled "Ethical, Legal and Social issues in Genetic Testing and Genetic Research".

The Office of Life Sciences thinks that the paper is well thought out and very comprehensive. However we would like to suggest that for Predictive Testing (point 2.3e), perhaps genotypes should be included in the definition with regards to individual therapy. Similarly for Susceptibility (or predisposition, point 6.34b) tests, perhaps individual susceptibility to drug effects or even adverse drug effects and toxicity should be included.

We hope that you would find the above feedback useful.

Yours sincerely

John

Professor John Wong
Director
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SINGAPORE NURSING BOARD

11 May 2005

Associate Professor Terry Kaan
Chairman
Human Genetics Subcommittee
Bioethics Advisory Committee

Dear Prof Kaan

REQUEST FOR FEEDBACK ON CONSULTATION PAPER ETHICAL, LEGAL AND SOCIAL ISSUES IN GENETIC TESTING AND GENETIC RESEARCH

Thank you for inviting the Singapore Nursing Board to give its views on the paper.

We would like to congratulate the Human Genetics Subcommittee for producing such a comprehensive paper. The paper has covered all the important aspects of genetic testing and genetic research.

A Board member has one comment on recommendation 7 (page 15). Normally in application forms (for jobs/insurance), the applicant has to make a declaration that he/she has submitted all the information (especially with regard to health or potential health risks e.g. diabetic parent) to the best of his/her knowledge. The paper could consider the legal implications should the applicant not disclose genetic test results which he/she knows.

Best wishes

Yours sincerely

Ms Ang Beng Choo
Registrar
Singapore Nursing Board

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