مجلس اكام اسلام سيغافورا
Majlis Ugama Islam Singapura
(Islamic Religious Council of Singapore)
Islamic Centre of Singapore • 273 Braddell Road • Singapore 579702 • www.muis.gov.sg • Tel : 6256 8188 • Fax : 6253 7572

MUI OOM/31/2

DID : 63591473
FAX : 62519197
17 May 2005

Associate Professor Terry Kaan
Chairman
Human Genetics Subcommittee
Bioethics Advisory Committee
20 Biopolis Way, #08-01 Centros
Singapore 138668
Fax : 6478 9581

Dear Prof. Terry Kaan,

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

We refer to your letter of 4 April 2005 to Haji Mohd Alami Musa, President Muis.

2 Our general view is that the paper is well balanced and fair in its assumptions and recommendations. We agree that proper legislation should be put in place to safeguard against any misuse and abuse.

3 Looking at the specifics of the paper, we further feel that there may be some issues that may have connection with the application of our Islamic Law, which may require our Fatwa (Legal) Committee to issue its opinion on them, such as :

3.1 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".
Concern: whether immediate family who have interest such as spouses and siblings have a right to be informed.

3.2 Recommendation 12:
"Preimplantation tissue typing, whether as a 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".

Concern: The matter requires religious opinion from Fatwa Committee

3.3 Recommendation 14:
"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".
Concern: This may have bearing on the Islamic's view on abortion.

3.4 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".
Concern: There could be religious and social implications, such as on marriage.

5 We are therefore convening the Fatwa Committee to deliberate the above issue to offer its religious opinion on them. We expect to have them in a months' time and will revert to you soon after that.

Yours sincerely,

SYED AHMAD BIN SYED MOHAMED
for SECRETARY
MAJLIS UGAMA ISLAM SINGAPURA

BACHumanGenetics

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MUI OOM/31/2

DID : 63591473
FAX : 62519197
16 June 2005

Associate Professor Terry Kaan
Chairman
Human Genetics Subcommittee
Bioethics Advisory Committee
20 Biopolis Way, #08-01 Centros
Singapore 138668
Fax : 6478 9581

Dear Prof Terry Kaan,

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

Further to our letter of 17 May 2005, we are pleased to enclose herewith the opinion of MUIS Office of Mufti which has consulted the views from Muis Fatwa Committtee on the Consultation Paper on Ethical, Legal and Social Issues in Genetic Testing and Genetics Research.

2 We have no objection for the said opinion to be published by the Bioethics Advisory Committee.

Yours sincerely,

Syed Ahmad Bin Syed Mohamed
for Secretary
Majlis Ugama Islam Singapura

BACHumanGeneticsFatwaOOM

Respon Jawatankuasa Fatwa
Terhadap Saranan Jawatankuasa Penasihat Bioetika Mengenai Ujian Baka

Pendahuluan :

Jawatankuasa Fatwa mengalu-alukan setiap perkembangan ilmu pengetahuan secara khusus dalam bidang sains hayat. Pendekatan ini diambil atas dasar bahawa agama Islam adalah agama yang bertunjangkan ilmu pengetahuan. Selama mana ilmu tersebut tidak menyalahi dua syarat di bawah ini, maka ianya dibolehkan iaitu :

i. Ianya tidak ada tegahan daripada Syara' melalui nas Al-Quran atau As-Sunnah,
ii. Ianya tidak mendatangkan mudarat kepada manusia.

Apa jua ilmu dan kajian yang mendatangkan manfaat kepada masyarakat Islam dan menolak keburukan daripada mereka, di situlah terletaknya syariat Allah. Imam Ibnu Al-Qayyim berkata:

فإن الشريعة مبناها وأساسها على الحكم ومصالح العباد في المعاش والمعاد، وهي عدل كلها، ورحمة كلها، ومصالح كلها، وحكمة كلها، فكل مسألة خرجت عن العدل إلى الجور، وعن الرحمة إلى ضدها، وعن المصلحة إلى المفسدة، وعن الحكمة إلى العبث، فليست من الشريعة..."

Ertinya : "Maka sesungguhnya syariat itu terbina atas asas hukum dan maslahat manusia di dunia dan akhirat, Syariat itu keseluruhannya adalah adil, keseluruhannya adalah rahmat, keseluruhannya adalah maslahat, dan keseluruhannya adalah hikmah. Maka setiap masalah yang keluar dari keadilan kepada kezaliman, dari rahmat kepada sebaliknya, dari maslahat kepada keburukan dan dari hikmah kepada sia-sia, maka masalah itu bukan daripada Syariat..." [1]

Dr Ali Qurra Daghi di dalam artikel beliau mengenai perubatan baka juga berkata :

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[1] Ibn al-Qayyim al-Jawziyyah, *I'lām al-Muwaqqi'īn, jilid 3 ms 797, Maktabah Nazar Mustafa al-Baz, Makkah – Riyadh.*

فالشريعة الإسلامية مبنية على تحقيق المصالح ودرء المفاسد، فأينما تكن المصلحة الحقيقية فـثَمَّ شرع الله تعالى. فالشريعة عدل كلها، ورحمة كلها، وخير كلها، فأي شيء فيه الضرر والقسوة، أو الظلم والجور، أو المفسدة والمضرة، فليس من هذه الشريعة.

Ertinya : "Syariat Islam terbina atas memastikan wujudnya maslahat dan menolak keburukan. Maka di mana sahaja terdapat maslahat yang pasti, maka di situlah terletaknya syariat Allah Ta'ala. Syariat itu keseluruhannya adalah adil, keseluruhannya adalah rahmat dan keseluruhannya adalah kebaikan. Maka apa-apa perkara terdapat di dalamnya bahaya, kekerasan, kezaliman, penyelewengan, keburukan dan kemudaratan, maka itu semua bukan daripada Syariat."[2]

Pandangan Jawatankuasa Fatwa Terhadap Kertas Saranan Jawatankuasa Penasihat Bioetika Mengenai Isu Etika Ujian Baka.

Jawatankuasa Fatwa telah berbincang dan meneliti kandungan kertas saranan mengenai isu "Etika, Perundangan dan Sosial dalam Ujian dan Kajian Baka" (*Ethical, Legal and Social Issues in Genetic Testing and Genetics Research)* yang disediakan oleh Jawatankuasa Penasihat Bioetika, Singapura (*The Bioethics Advisory Committee)*. Hasil daripada perbincangan tersebut Jawatankuasa Fatwa berpendapat bahawa secara dasar semua 24 rekomendasi yang terkandung di dalam kertas saranan rekomendasi etika perubatan ujian baka (*Genetic Testing*) boleh diterima kerana ianya tidak bercanggah dengan prinsip-prinsip Syara' dan al-Urf. Ianya merupakan isu teknikal yang tiada menyentuh hak individu dan tiada pula unsur paksaan. Sehubungan dengan itu, Jawatankuasa Fatwa secara dasar berpendapat bahawa ujian baka ini adalah harus.

Jawatankuasa Fatwa juga telah memberikan penekanan terhadap beberapa rekomendasi yang dirasakan ada kesan terhadap pandangan agama yang perlu diperincikan dan diperjelaskan lebih lanjut. Ianya seperti berikut :

Rekomendasi 3 :

[2] http://www.islamonline.net/Arabic/contemporary/2002/07/article02.shtml

Jawatankuasa Fatwa mengalu-alukan rekomendasi ini yang antara lain menekankan bahawa ujian baka harus dijalankan secara pilihan dan tiada unsur paksaan.

Rekomendasi 5 :

Jawatankuasa Fatwa juga sangat mengalu-alukan dengan kandungan rekomendasi ini yang menyatakan bahawa kedua ibu-bapa tidak digalakkan melaksanakan ujian baka untuk anak-anak mereka. Ujian baka tersebut diserahkan kepada pilihan anak-anak mereka setelah mereka sampai usia matang.

Rekomendasi 7 :

Saranan rekomendasi ini agar natijah atau keputusan ujian baka seseorang tidak didedahkan kepada mana-mana pihak ketiga juga disetujui oleh Jawatankuasa Fatwa.

Rekomendasi 12 :

Jawatankuasa Fatwa berpendapat bahawa melakukan salinan tisu bagi menghasilkan rawatan pada masa depan adalah sesuatu yang harus. Sehubungan dengan itu, contoh yang diandaikan bagi pasangan yang ingin mendapatkan anak kedua yang dihasilkan daripada salinan tisu bagi tujuan merawat penyakit anak pertama mereka adalah dibolehkan, ianya termasuk salah satu daripada bab ikhtiyar mencari rawatan. Namun, perlu diambil perhatian bahawa perlaksanaannya hendaklah tidak menimbulkan kemudharatan kepada yang terlibat.

Rekomendasi 14 & 15 :

Daripada rekomendasi ini, timbul pertanyaan tentang hukum melaksanakan Diagnosa Baka Sebelum Bersalin *(Prenatal Genetic Diagnostic)* untuk mengetahui kecacatan kandungan dan mengenalpasti penyakit serius. Jawatankuasa Fatwa dalam hal ini berpendapat bahawa secara dasar tiada halangan bagi setiap individu untuk menjalankan *Prenatal Genetic Diagnosis.* Sekiranya keputusan atau natijah *Prenatal Genetic Diagnosis* menjelaskan terdapat kecacatan ke atas kandungan atau menghidapi penyakit yang serius, maka Jawatankuasa Fatwa memberi saranan agar setiap individu Muslim

mendapatkan nasihat pakar agama bagi mengelakkan sebarang keputusan yang melanggar Aqidah, Syariat dan etika Islam yang bakal dibuat oleh individu tersebut.

Rekomendasi 17 :

Daripada rekomendasi ini, timbul pertanyaan hukum menjalankan Ujian Ramalan *(Predictive Testing)*. Jawatankuasa Fatwa dalam perkara ini berpendapat bahawa secara dasar tiada halangan bagi setiap individu menjalankan *Predictive Testing*. Sekiranya keputusan atau natijah *Predictive Testing* menjelaskan terdapat penyakit yang tiada ubatnya di masa akan datang, maka Jawatankuasa Fatwa memberi saranan agar setiap individu Muslim mendapatkan nasihat pakar agama bagi mengelakkan sebarang tindakan yang melanggar Aqidah, Syariat dan etika Islam dan bagaimana menghadapi situasi ini menurut pendirian agama.

Nota disiapkan oleh,
Kamaruzaman Afandi

Diedit oleh,
Ustaz Mohd Murat Md Aris

10 Jun 2005

TRANSLATION

THE FATWA COMMITTEE'S RESPONSE TO THE PROPOSAL BY THE BIO-ETHICS ADVISORY COMMITTEE ON GENETICS TESTING

INTRODUCTION

The Fatwa Committee welcomes all advancements in knowledge, in particular, in the field of life sciences. The Committee adopts this view as Islam is a religion premised on knowledge. The knowledge is deemed acceptable so long as it does not violate two fundamental conditions stated below, namely :

i. It (the knowledge) is not expressly prohibited by Islamic law through the injunctions in the Holy Qur'an or the Prophetic Tradition (As-Sunnah)
ii. It does not cause harm to mankind

The Syariah of Allah resides in any knowledge and research that promotes welfare of the human society or eradicates harm from it. Imam Ibn Al-Qayyim said :

(Arabic Text)

" The Syariah (Islamic Jurisprudence) is established on the basis of laws and in the promotion of the well-being of mankind in this world and the hereafter. The Syariah, in its entirety, is about the promotion of justice, blessing, benefit to mankind and wisdom. Therefore, solutions to problems that inhibit justice from being served, and that do not promote justice, the spirit of blessing, the needs and welfare of mankind and wisdom, do not constitute Syariah " [1]

Dr Ali Qurra Daghi in his article on genetic medicine also said :

(Arabic Text)

" Islamic Syariah is established on the principle of ensuring the preservation of the well being of mankind and alleviation of evil. Therefore, wherever well being resides, that is where the Syariah resides. Syariah,in its entirety, is about justice, and brings forth blessing and goodness. Therefore anything within which lies

danger, compulsion, cruelty, deviation, evil and harm does not constitute the Syariah." [2]

The Views of The Fatwa Committee In Respect of The Recommendations of the Bioethics Advisory Committee on the Issue of The Ethics of Genetics Testing

The Fatwa Committee has deliberated and examined the contents of the recommendations regarding the "Ethical, Legal and Social Issues in Genetic Testing and Research prepared by the Bioethics Advisory Committee. As an outcome to their deliberation, the Fatwa Committee is of the view that, in principle, all the 24 recommendations contained in the medical ethics recommendations on genetic testing set out in the paper are deemed acceptable as they do not violate any of the principles of Syara' (Islamic Laws) and al-Urf (customs). They constitute technical issues that do not infringe upon the rights of individuals and with no element of coercion present. Accordingly the Fatwa Committee opines that, in principle, genetic testing is permissible.

However, the Fatwa Committee wishes to emphasize a number of recommendations that it felt needed further explanation and elaboration as they may have religious implications. These are as follow:

Recommendation 3 :

The Fatwa Committee welcomes this recommendation which, among others, emphasizes that genetic testing must be conducted on a selective/ voluntary and not by coercion.

Recommendation 5 :

The Fatwa Committee also truly welcome the content of this recommendation which states that both the parents are not recommended to perform genetic testing for their children. The choice for genetic testing is left to the children themselves when they have reached a mature age/age of discretion.

Recommendation 7 :

The suggestion made in this recommendation that the result or outcome of a person's genetic testing should not be disclosed to a third party is also concurred by the Fatwa Committee

Recommendation 12 :

The Fatwa Committee is of the opinion that tissue typing in order to produce remedy/treatment for the future is a permissible act. Accordingly, the example cited of a couple wishing to have a second child made possible through tissue

typing for the purpose of treating the disease of their first child is deemed acceptable as it falls into the category of efforts taken in finding a treatment. However, it must be noted that the procedure must not endanger the lives of parties involved.

Recommendations 14 & 15

These recommendations raise the question of the ruling governing Prenatal Genetic Diagnosis to ascertain defects during pregnancy as well as identifying serious diseases. The Fatwa Committee in this instance is of the opinion that, in principle, there is no objection to and individual to undergo Prenatal Genetic Diagnosis. If the result or outcome of the Prenatal Genetic Diagnosis clearly demonstrates that there are defects or serious disease to the pregnancy, the Fatwa Committee proposes that every individual Muslim should obtain expert religious counseling/advice to avoid making any decision which violates the Islamic Faith, Laws and Ethics that may be committed by the individual concerned.

Recommendation 17 :

This recommendation raises the issue of the ruling governing Predictive Testing. On this subject, the Fatwa Committee is of the opinion that, in principle, there is no objection for every individual to undergo Predictive Testing. If the outcome or results of the Predictive Testing clearly show the presence of untreatable/ incurable diseases in the future, the Fatwa Committee proposes that every individual Muslim should obtain expert religious counseling/advice to avoid making any decision which would violate the Islamic Faith, Laws and Ethics and to be informed how to manage this situation from the religious perspective.

Notes prepared by:
Ustaz Kamaruzaman Afandi

Edited and approved by
Ustaz Mohd Murat Md Aris

10 June 2005

National Council of Churches of Singapore
新加坡基督教會協會
சிங்கப்பூர் திருச்சபைகளின் தேசிய மன்றம்

12th May 2005

By Fax & Mail

Judge Richard Magnus
Deputy Chairman
Bioethics Advisory Committee
20 Biopolis Way, #08-01 Centros
Singapore 138668

Dear Richard

A CONSULTATION PAPER
ETHICAL, LEGAL AND SOCIAL ISSUES IN GENETIC TESTING AND GENETICS RESEARCH.

Thank you for your letter of 27th April 2005.

I am attaching herewith our comments on the above paper.

Please note that the following two members from NCCS will be attending the dialogue session on 17th May 2005 at 3.30 pm.

1. Dr Roland Chia (TTC)
2. Prof Soong Tuck Wah (Neuroscience Centre)

We apologise for the delay in submitting this information.

Yours sincerely

Rt Rev Dr John Chew
President, NCCS

Encl.

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Feedback on the BAC Consultation Paper entitled, 'Ethical, Legal and Social Issues in Genetic Testing and Genetic Research'

INTRODUCTION

Genetic testing for diagnosis or research is an important advancement in science and medicine whose promises and perils we are unable to fully appreciate at this point in time. As such the National Council of Churches (NCCS) welcomes the efforts of the Bioethics Advisory Committee (BAC) to provide appropriate ethical guidelines to prevent abuse of the available technologies and misuse of the genetic information that is obtained by them. The NCCS therefore applauds that the BAC sees the need to ensure that 'genetic testing is conducted with due consideration and protection of the individual's interests and rights'.

Below are some brief comments on the Consultation paper entitled, 'Ethical, Legal and Social Issues in Genetic Testing and Genetic Research' prepared by the BAC. While the NCCS supports most of the stipulations delineated in the paper and broadly endorses most of the recommendations, we wish to highlight several major concerns and raise other issues that are not directly addressed.

SOME MAJOR CONCERNS

Preimplantation Genetic Diagnosis

The main issue surrounding preimplantation genetic diagnosis (PGD) from the standpoint of the NCCS has to do with the nature of the early embryo or zygote. Here we reiterate our position that the zygote from the moment of conception is a human being bearing the image of God and must therefore be accorded the same respect due to all human beings. The zygote of human parentage is a human being because of its source, and because it cannot articulate itself into another animal. Furthermore, the zygote is growing, and therefore alive. These two observations lead to the conclusion that the one-celled zygote is a human type of life. Furthermore its particular combination of genetic instruction is unique, making it an individual.

The NCCS does not support the creation of embryos through *in vitro fertilization* (IVF) because the practise requires numerous fertilisations and the destruction of human embryos. The practice presupposes hyperovulation in which a number of ova are withdrawn from the woman, fertilised and cultivated *in vitro* for a number of days. Not all the fertilised ova are transferred into the uterus of the woman. Some embryos, which

are called 'spare', are either destroyed or frozen. These frozen embryos may be used for research and later destroyed. Furthermore, the question of ownership pertaining to the embryos that are left frozen in laboratories becomes problematic, especially in cases where the couple does not wish any further *in vitro* attempts or when there is a divorce or when one of the parents dies. For these reasons, the NCCS cannot support *homologous* IVF, even though it poses less ethical problems than *heterologous* procedures, which uses third party reproductive materials.

Preimplantation Tissue Typing

Without a doubt, the benefits and potentials of Preimplantation Tissue Typing (PTT) are staggering, given its ability to save lives. These benefits notwithstanding, the NCCS has serious reservations and therefore does not support this procedure. The NCCS maintains that the objection to PTT that is briefly discussed and answered in 6.22 must be given more careful and serious consideration. No human being should be seen as a commodity serving utilitarian ends. The language of the HFEA definition suggests commodification when it describes PTT as the procedure which 'allows the selection of embryos in order to bring about the birth of a child who can provide a matched tissue donation to an existing sibling ...' The underlying philosophy of the commodification of human beings is a utilitarianism which regards humans as objects that are not valued for who they are but for their usefulness. Such approaches should never be countenanced no matter how 'great' or 'noble' the ends may be. The theological vision of our humanity espoused by the Christian Tradition demands that each and every human being is treated as inherently valuable. This vision promotes an egalitarianism that treats persons as ends and never merely as means to an end.

The paper mentions lack of evidence to support concerns over commodification in PTT. But this begs the question regarding the way in which that evidence is gathered and analysed since PTT was only approved in 2001 in the UK, the number of PTT approved may be limited and the children born after PTT must be young. How can the assertion in 6.22 be justified based on limited data and not supported by more robust research?

It is in a sense true to say that 'parents who conceive a child to save a life may be on higher moral ground than those who procreate as an unanticipated consequence of sexual pleasure or for some selfish purpose' (6.22). But from the standpoint of moral argument, this logic is flawed. An act that is morally unacceptable is wrong even if it may not be as repugnant as other morally unacceptable acts. The more fundamental question therefore is whether an act, although in some ways more superior to others, is *in itself* morally unacceptable. We maintain that to bring about the birth of a child with the appropriate genotype in order that he may provide a matched tissue donation to a sick child is morally unacceptable.

The UK HFEA 2001 recommendation seeks to limit the use of the PTT child for cord blood only and not for other tissues and organs. This constraint, however, can be breached, especially if the affected sibling later develops organ failure. The PTT child would then be under tremendous pressure to be an organ donor because matched organ

transplantation is life-saving. But even if this constraint is not breached, and the PTT child is used only to provide cord blood, the fundamental objection remains: a child must be received as a gift; providing matched tissue donation must never be the basis of its existence.

The paper deals with the purported love of the parent for the child, but fails to consider the possible impact on the PTT child when he discovers that part of the reason for his existence was for deriving matched tissues, although for an altruistic and noble cause.

The Christian Tradition maintains that children are gifts from God who must be accepted with thanksgiving and gratitude. They are not the products of the parent or the scientist, and they do not exist to fulfil their parents' projects. There is therefore a sense in which parents should see their child not simply as 'their' child; that is, the child does not simply exist for their happiness or sense of fulfilment. The child exists for itself because it has its own integrity and dignity as a person. To exert control over the genotype of the embryo so that it may donate a matched tissue to an existing sibling is already to treat it as a product, as a means to an end. This subtle shift in society's attitude towards children should never be taken lightly, for the serious consequences that will result in time would change the very moral fabric of our society.

Prenatal Genetic Diagnosis

While the NCCS broadly supports prenatal genetic screening and diagnosis, it does not do so unreservedly. Prenatal genetic screening is morally appropriate as long as the benefit of obtaining the information is greater than the risks involved in the test. While many have argued that PND has the benefit of preparing the couple for their child, it also creates a certain distance between them and the unborn child. This is because before the results of the tests are out, the couple does not yet know whether they are going to sustain their bond with the unborn child or whether they will walk away. Under the abortion assumption, PND makes the commitment between the parent and the child conditional. We must never under-estimate what this conditional commitment symbolised by PND entails, and its implications to society. PND cannot avoid the charge of providing impetus to the 'quality control' mindset, where the unborn child is already seen as a product that must satisfy the expectations of his parents. For this reason, PND far from helping the couple prepare for their child, is in fact poor preparation for parenthood.

What parents do with the outcome of the test and the information gleaned from it is very important. Needless to say, the NCCS cannot countenance the termination of the pregnancy as a morally acceptable option for dealing with a foetus with genetic disorders (Recommendation 14). Unfavourable results should not compel the couple to resort to abortion. The abortion assumption, however, looms large in the literature concerning PND. The term 'aminocentesis', for instance, which is often employed in such literature not only refers to testing but also assumes that the couple will authorise abortion if the foetus is found to have some genetic defect. The general argument frequently made by health officials that PND reduces the incidence of genetic diseases is also underpinned by the abortion assumption. The abortion assumption, to be sure, is understandable. To learn

that their unborn child has a genetic defect is a crushing disappointment that many couples would like to put behind them. Furthermore, most couples wish to avoid the emotional, physical and financial strain of raising a handicapped child. To them, abortion may appear to be the best solution and even a reasonable course of action.

The ethical justification for ending the child's life because of the discovery that the child is not healthy *in utero*, however, requires serious reconsideration for the following reasons:

1. The couple must realise that there is a margin of error in PND. The AFP test, for instance, is notorious for its false positives and false negatives. Amniocentesis likewise is not 100% accurate.
2. Even if the tests are accurate, it is difficult to predict the degree of disability in the child. For example there are various degrees of abnormality in children with Down Syndrome, some quite severe while others very mild.
3. The abortion assumption is based on the quality of life argument. But it is presumptuous to conclude that genetically or otherwise disabled persons are not able to enjoy a certain quality of life and therefore do not deserve to live.
4. Finally, and most importantly, abortion should never be an option because a genetically deformed foetus is still a human person.

As stated above, according to the Christian understanding, the human embryo at the moment of conception is already a human being created in the image of God. On this premise, we conclude that abortion is tantamount to the killing of an innocent human being. But the Christian rejection of abortion does not have to do exclusively with the question of the personhood of the embryo or foetus, although this consideration is very significant. It is also based on the profound view that the whole of life must be seen in light of God's creative and redemptive act. The unborn child in his mother's womb must be seen as God's creation, a gift from the hands of the Creator. In this sense, the unborn child in the womb cannot be subjected to our – i.e., his mother's, his father's, the doctor's and society's – evaluation, and his future cannot be based on whether or not we 'want' the child. Our estimate of the child and his worth must be brought into alignment with God's will for the child and his estimate for him.

According to the Christian understanding, the diseases and genetic deficiencies that affect our children and us are the result of human rebellion and sin which disrupts the harmony and balance in our world. Christians are not oblivious or insensitive to the sufferings of a couple whose unborn child is carrying a gene that predisposes him to Huntington disease, for instance. Neither are Christians immune from similar suffering themselves. But Christians would readily agree with Socrates who said that it is better to suffer evil than to do it. It is easy to rid ourselves of the child who is unwanted and so save ourselves (and the child, so the argument goes) from pain and misery. But by so doing we ironically surrender ourselves unwittingly to the very destructive powers in the world that we detest and resist.

OTHER ISSUES

Genetic Information

The NCCS concurs that genetic information derived from clinical genetic testing should be confined to a health care context, and that such information should be regarded as medical information and that 'the highest ethical standard should be applied in its derivation, management and use' (Recommendation 1). We agree with the point made in 2.11 that when used by a third parties 'for non-medical purposes' (i.e., for research) genetic information should be 'accorded greater ethical and legal safeguards'. The problem that may arise here is that sometimes 'diagnostic investigations' and 'research' may overlap. For example, a project to retrospectively screen blood and archived tissues of sudden death victims for genes usually implicated for various forms of fatal cardiac arrhythmias[1] may be described as part of the 'diagnostic investigation' when it is actually research by a third party (parties). Clearer definitions of 'diagnosis' and 'research' must be forwarded in order to prevent abuses.

Informed Consent

The BAC rightly recognises the fact that obtaining informed consent before genetic testing has to do with the 'broader societal value of respect for persons' (3.5). It presents two exhaustive lists of information that must be made available to individuals before genetic testing is done, either for therapy (3.7) or for research (3.9). In Recommendation 3 of the paper, a distinction is made between consent for diagnosis and research. This distinction is important in order to prevent the use of excess blood or tissue samples obtained for diagnostic purposes for future research.

It is important that we go beyond the formal procedures of informal consent and begin to study the quality of informed consent in our community. Obtaining informed consent, is not a straightforward matter. In the first place, this exercise requires that the participant is competent enough to understand the relevant information and can choose according to his life plan. To be competent to make the necessary decision means that the individual must at least understand the information regarding the tests and the freedom to refuse them without penalty. Ethicists as well as researchers have found it difficult to assess the competence of participants when dealing with scientific procedures about which they know very little. This problem becomes more acute when the particular decision and its implications are varied and complex. Beauchamp and Childress maintain that it is important that there must be sufficient assurance that participants are indeed able to comprehend the information.[2] These authors are not requiring greater participant *ability*, but a clearer *verification* of that ability. Furthermore certain terms used by the counsellor or researcher can also influence the decision of the participants. For instance, terms like 'therapy' and 'treatment' may imply greater effectiveness than has yet been shown. It is

[1] The alleged genes are KCNQ1, HERG, KCNE1, KCNE2, SCN5A, ryanodine receptor 2 (RYR2) and calesquestrin 2 (CASQ2).

[2] See Tom L. Beauchamp and James J. Childress, *Principles of Biomedical Ethics*, 4th ed. (New York: Oxford University Press, 1994), 142-169.

them in blocks of wax for periods of ten years or more. Genetic material can be obtained indiscriminately and irresponsibly from these samples if no proper ethical and legal safeguards are in place.

Supply of Genetic Testing

The BAC recognises the availability of certain types of genetic testing overseas as well as the prospect of 'do-it-yourself' devices that enable such testing to be done. In following the 2003 UK HGC report, the BAC wisely recommends that genetic testing 'should be conducted through the intermediation of a qualified healthcare professional' while strongly discouraging 'the advertising of genetic tests by manufacturers or suppliers to the public' (Recommendation 8). The paper also announces that a regulatory framework for the registration of genetic testing devices and services is being put together by the Medical Device Regulation (CMDR) of the Health Sciences Authority (HSA).

Even with a sound regulatory framework in place individuals cannot be prevented from gaining access to genetic testing. Perhaps the BAC should also recommend guidelines for post-testing counselling, especially probabilities counselling for those who have taken these tests from providers that are not registered with MOH or HSA. Such persons may be advised to undergo similar tests again with authorised centres or hospitals. Counselling should also help individuals to deal with unexpected information, that is, when tests done for a particular condition reveals other conditions. It should help individuals to make decisions regarding his future and that of his family, since it is often said that genetic tests offer less fate and more responsibility.