March 10, 2000

Rhonda Ferderber
Director Special Projects Division (RGTs)
Health Canada Policy and Consultation Branch
Address Locator 0910C
Ottawa ON K1A 0K9

Dear Ms. Ferderber,

Re: Reproductive and Genetic Technologies Workbook Issues and Related Questions; Response of Canadian Bar Association's National Health Law and Family Law Sections

We are writing on behalf of the National Health Law and Family Law Sections of the Canadian Bar Association. We have reviewed the *Workbook -- Issues and Related Questions -- Reproductive and Genetic Technologies (RGTs)* and provide our initial response below.

At the outset, we wish to express our concerns concerning the short period of time given for response to this document. We appreciate the opportunity to comment during the policy development process. However, the regulation of RGTs is an important, complex and controversial issue and requires a reasonable time frame for meaningful response from stakeholders. This is particularly true for volunteer organizations such as the CBA. The time provided for response only allows us to provide a brief initial response. We trust there will be further opportunities to provide more detailed and considered comments.

Before responding to the specific questions set out in the Workbook, we wish to make a general observation that the Workbook does not appear to have raised issues which are important in the family law context and which may also require legislative revision. For example, there is no discussion of the issue of legal parentage when technology has been used in order to achieve pregnancy, including custody and access rights, eligibility under succession laws and wills, and child support obligations. There is some discussion of regulating rights and responsibility in the context of surrogacy contracts, but such discussion does not recognize the complex issues of parentage that arise such as when the childbearing mother may have contributed her womb, but not her ovum. Generally, our family law needs to catch up to the reality of medically assisted procreation. We recognize that there may be federal/provincial/territorial constitutional considerations involved in some of these family law issues,

however we believe that the federal government should take a leadership role in ensuring a common approach across the country.

Question 1

We have not answered questions 1.3 or 1.5, which are directed at provincial and territorial governments, or 1.6, which is directed at other types of stakeholders.

1.1 What comments do you have regarding the proposed list of prohibitions? Do you have any issues to raise? Would you propose any deletions? Are there any omissions? Why?

and

1.2 What comments do you have with respect to the list of regulated or controlled activities? What are your comments regarding the section on regulations?

First and foremost, the legislation has to articulate its purpose clearly. This purpose should include a clearly stated rationale for distinguishing between prohibited actions and regulated actions. What is the "mischief" that calls for government action? What makes some behaviour sufficiently egregious to warrant outright prohibition? Without this context, it is difficult to distinguish between the kinds of activity which should be prohibited, the kinds of activity which should be regulated and the kinds of activity which should be left alone.

In the CBA's April 1997 submission on Bill C-47, we expressed a concern about using criminal sanctions to address many RGT activities. We have a continuing concern about the use of criminal law penalties, which represent the most serious sanctions in our legal system. The criminal law is a blunt and inflexible instrument which should be used sparingly and then only where there is a serious impact on the welfare of Canadians.

Further, the legislation needs to define clearly the procedures that are considered criminal in nature. Canadians should not have to face criminal penalties without knowing precisely the behaviour which is prohibited. Further, unclear definitions of criminal behaviour could have a chilling effect on legitimate research and procedures. The list of proposed prohibited activities in the *Workbook* contains a number of items which are defined in a vague and overbroad fashion. They need to be clarified.

The government should consider defining "human" or "human being" in this context. This might be useful, for instance, where activities such as cloning are prohibited "for the purpose of

creating another human being". Does "human being" include parts of a human being? Does it include persons with no brain functions?

1.4 Do you have any questions about the section on privacy?

Children have the right to know their medical and genetic heritage. They should be able to find out whether there is a history of medical or genetic conditions in their lineage. We believe the right to know supercedes any privacy interests of donors, although we would not extend this right (except perhaps in exceptional circumstances) to include the identity of the donor.

Organizations providing a controlled activity should be entitled to collect medical and genetic information from donors and persons making use of assisted reproductive procedures in accordance with any regulations. Donors and persons making use of assisted reproductive procedures should be required to answer any of these inquiries.

Question 2

2.1 What are your comments on the proposed list of areas for regulatory development? Would you propose adding to the list? Would you propose any deletions?

(a) Surrogacy

We believe the legislation should regulate commercial surrogacy. We repeat the CBA's recommendations to the Royal Commission on Reproductive Technologies, which were reiterated in our brief on Bill C-47:

i) There should not be a specific ban on "surrogacy" arrangements.
ii) "Surrogacy" arrangements should be rendered unenforceable.
iii) These arrangements should be assimilated as far as possible into the adoption model, thereby allowing the birth mother at least ten days after birth to decide whether to proceed with the agreement.
iv) There should be no money or consideration of any kind payable with respect to these arrangements. All payments for adoption should be deemed to be illegal.
v) A legislated exception should be made to the presumption of paternity provisions and to the consent to adoption provisions in the case of a "surrogacy" arrangement which the

birth mother decides to respect, so that the intended social parents are the legal parents and other presumptive parents have no status.

vi) The meaning of "written agreement" in the family law legislation as it pertains to custody matters should be amended to exclude "surrogacy" agreements, except as invoked by the birth mother. In all respects, the intended social parents in a "surrogacy" arrangement should be in no better position than other proposed adoptive parents.

vii) The proposed adopting parents should have no rights of access if the birth mother chooses not to respect the agreement and does not relinquish custody.

viii) If the birth mother chooses to respect the "surrogacy" agreement, offers to relinquish custody to the proposed adopting parents, is turned down for any reason, and does not otherwise relinquish custody of the child, she should be entitled to claim maintenance on behalf of the child from the proposed adopting parents and their estate.

(b) Licensing regulations -- testing and consent

Two important issues for RGT service providers are the ability to test donors for genetic disorders and infectious or transmissible diseases, and the appropriate form of consent for patients to undergo RGT procedures.

We believe that the most appropriate way to deal with these issues is through the licensing scheme for RGT service providers. The licensing body will need to ensure the appropriate testing procedures and methods and forms of obtaining consent are in place prior to issuing a licence.

The methods and forms of consent will likely have to be different from those in place for regular medical procedures. This is in part because RGTs deal not just with medical procedures performed on the donor but also on procedures performed on parts removed from the donor. Consent will have to address such issues as: potential side effects from fertility drugs, uncertainty of procedures such as superovulation, use of anaesthesia for egg retrieval, increased incidence of surgical births, intrusive monitoring and the success rate of the procedure. In addition, one issue which may have to be addressed is the extent to which a potential donor may grant the ability to consent to a third party through a power of attorney.

2.2 Have you done any development of standards that pertain to the proposed areas? Could your work be used as a model or template for future regulatory work?

The CBA has not developed any standards in this regard.

2.3 From your perspective, which of the proposed areas for regulation need to be developed as a priority? Which of the proposed areas for regulation, if any, could wait to be developed?

All of the areas of RGT regulation are interrelated. Licensing of RGT service providers goes hand in hand with regulations concerning specific procedures those service providers can undertake. These specific procedures can depend on "transactions" -- the collection, storage, processing and distribution of gametes, embryos and foetuses. Research has an inevitable link with RGT service providers, as it is the means by which new procedures develop.

It is therefore difficult to isolate one area as being more important than others. We therefore recommend that regulation proceed at the same time for all areas of RGTs.

Question 3

We have not answered question 3.2 about enhanced federal/provincial/territorial co-operation.

3.1 What should be the relationship for the regulatory body and Health Canada? Why?
We favour an agency that is autonomous from Health Canada. Given the unique nature of RGTs, it is important to have an agency which has a high profile and which can set -- and be perceived as setting -- its own priorities independently from Health Canada. An independent body will be able to devote its financial and human resources to the RGT issue without being side-tracked by other priorities within Health Canada. As a result, it will be better able to respond quickly to rapid changes in the RGT environment.

We also believe an independent agency will have an easier time incorporating a multi-disciplinary approach to the RGT issue, which might include representation from the academic, scientific, industrial and legal communities as well as from the public at large.

3.3 For your preferred model, what are your thoughts about an advisory structure?

The independent agency should have a panel of advisors who sit in an informational, as opposed to decision-making, capacity. The job of the advisory panel would include alerting the agency to new developments and providing advice on difficult issues faced by the agency. The panel would be made up of people knowledgeable in the science and research of RGTs, as well as bio-ethicists and lawyers familiar with RGT issues.

3.4 What are your comments about the main functions of the regulatory body? Are there any functions, or parts thereof, that you would consider undertaking yourselves? Are there any functions which lend themselves to being contracted out?

The agency should have a number of functions. These would include:

(a) setting standards for the handling and use of reproductive material in medical research and practice and advising the government on any necessary changes to RGT regulations;
(b) licensing RGT service providers and researchers, including setting licensing fees and conditions;
(c) enforcing the legislation, including regularly inspecting facilities to ensure compliance, investigating alleged breaches of the legislation, revoking or amending licences and recommending criminal prosecutions to the Attorney General, where appropriate;
(d) educating and consulting with the public on RGT issues;
(e) maintaining information registries such as donor and offspring, fertility treatment registry, surveillance of fertility drugs and procedures used to treat infertility.

Of all of the above powers, we believe the enforcement power is going to involve the most controversy. It therefore demands a significant amount of attention when the legislation is being drafted, particularly when quasi-criminal powers such as search and seizure are being contemplated.

Finally, we would like to point out that any new agency must receive sufficient funding to carry out its functions. The new agency will be dealing with issues and practices which strike at the heart of our fundamental ideas and beliefs and it would simply be unacceptable for it to be hamstrung by inadequate resources.

Question 4

4.1 What suggestions/expectations do you have for continued cooperation on this initiative?

The CBA has been involved in the RGT issue for a long time and has presented thoughtful and comprehensive submissions on government initiatives in this area. We would expect to continue to be consulted throughout the legislative process and would welcome the opportunity to review draft legislation before it is introduced. We will certainly be reviewing any legislation after it is introduced with an eye to preparing submissions for any Parliamentary committee hearings.

We must reiterate, however, that the CBA is a volunteer organization which is comprised of practising lawyers and jurists and which deals with a wide range of issues beyond RGTs. It is very important that we, and other volunteer organizations, be given reasonable time frames to comment on proposed legislation or on issues as they arise. RGT issues are complex and involve questions which touch the heart of deeply held personal beliefs in our society. They need time for consideration and reflection.

4.2 In summary, what are your expectations for the key areas of federal leadership on this issue?

Again, it is not possible for us to isolate key areas, as all areas demand action and leadership from the federal government.

We thank you for the opportunity to provide our input. If you have any further questions or comments, please do not hesitate to contact Richard Ellis, a staff lawyer in our National Office. He can be reached at (613) 237-2925, ext 144; fax (613) 237-0185; email richarde@cba.org.

Yours truly,

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