

Canadian Bioethics Society

NEWSLETTER

Volume 5, Number 2

August 2000



PRESIDENT'S LETTER

Marianne Lamb 1999-2000

Last October, a number of topics were discussed at the Annual Business Meeting of the Canadian Bioethics Society in Edmonton that have led to follow-up by the Executive Committee. At a recent teleconference meeting of that Committee, we were pleased to welcome President-elect Christine Harrison, who will become President of CBS next October. A new Constitution was adopted at the Annual Meeting, but there were some issues raised by members about one section — the definition of “ethicist” and categories from which Executive Committee members are drawn. A working group, led by Kathleen Glass, has considered alternate wording for this section of the Constitution and a report will be brought forward for discussion at the next Annual Meeting. We will complete the implementation of the new structure for CBS this Fall with the election to several new

positions and you will see an item from the Nominating Committee in this newsletter.

Employment issues for bioethicists was the topic of a lunch-time colloquium at the October meeting and a motion was adopted that CBS establish a Working Group to look at these issues and to report back the following October. We have had some difficulty establishing the group, but we hope to have the work in progress soon. It is doubtful that a final report will be ready for October, but while that work continues, there are plans to have a workshop session on the topic at the Conference in the Fall.

Edith Delury and her Planning Committee have been working hard to prepare for the 12th Annual Canadian Bioethics Society Conference. More information is available in this issue of the Newsletter and at the CBS website. We do

hope that you will be attending the Conference and we look forward to seeing you in Quebec City.

[<m124@post.queensu.ca>](mailto:m124@post.queensu.ca)

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Canadian Bioethics Society NEWSLETTER

Charitable Registration #0876649-09

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Christine Harrison	President-Elect
Paula Chidwick	Communications Officer

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Kathleen Glass
Chris MacDonald (Student Representative)

Newsletter Editor

Paula Chidwick

This newsletter is published in both French and English and is distributed to CBS members in their preferred language. Members can obtain an additional copy in the alternate language upon request.

Newsletter submissions in the form of articles, letters, book reviews, notices and events are welcomed.

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Paula Chidwick

Letter from the Editor

Paula Chidwick

In the last issue of the *CBS Newsletter* we had a number of articles examining issues on working conditions for bioethicists. Issues were raised, for example, about what should happen if a bioethicist should hold a view significantly different from or disliked by hospital administration and then is asked not to voice his/her view? As we continue the inquiry into this area it is worthwhile examining what other social, political and economic influences may affect working conditions and employment. Issues that arise for bioethicists do so in a context and awareness of the influences within this context will contribute to a better understanding of how we can proceed fairly and responsibly.

Eoin Connolly, an undergraduate student, offers some impressions of what he understands the role of a bioethicist to be. He also suggests that some sort of organization or union be formed so that bioethicists are protected for taking a "principled stance" and at the same time held accountable for the work they do.

Nancy Smith looks at how gender plays a role in how women perceive themselves in scientific careers. Her research follows what has happened to a number of women who have chosen careers in science.

We also have a submission from Jane Cawthorne who examines the interests of children as opposed to women in the issues that arise in new reproductive technologies. And, finally we have a submission from an international member Jose Goldim who writes about informed consent (or the lack of informed consent) in research protocols in Brazil.

There are a number of announcements, postings and advertisements in this issue. My thanks to all those who made submissions this year. If you are interested in making a contribution you may submit material to the editor at pchidwic@uoguelph.ca in Richtext format. See you in Quebec City!

<pchidwic@uoguelph.ca>

12th Annual Canadian Bioethics Society Conference

October 19-22, 2000 • Québec-Hilton – Québec, Qué.

THURSDAY, OCTOBER 19, 2000

Pre-Conference Workshop: Ethics and Psychiatry

8:30 - 9:00 **Registration**

8:30 - 17:30 **Workshop**

THURSDAY, OCTOBER 19, 2000

12th Annual Canadian Bioethics Society Conference

15:00 - 18:00 **Registration**

19:45 - 20:00 **CBS Conference Opening Ceremony**

20:00 - 21:00 **Keynote Speaker: J.-François Malherbe**
Directeur, Chaire d'éthique appliquée,
Université de Sherbrooke

21:15 **Opening Reception (cocktail)**

FRIDAY, OCTOBER 20, 2000

Advances in Medicine: The Fall of Humanism?

7:30 - 8:15 **Registration/breakfast** (provided)

8:30 - 10:00 **Plenary Session**

Marc-André Sirard (Director)
Raymond D. Lambert, François Pothier,
Univ. Laval
Centre de recherche en biologie de la
reproduction

10:00 - 10:30 **Break**

10:30 - 12:00 **Changing the Relationship with the
Human Body and Nature**

Concurrent Sessions

Symposium

*Production of Pharmaceutical Agents with
Transgenic Organisms*

Louis Vézina, Scientific Director, Medicago
François Arcand, Executive Director, Medicago
François Pouliot, Chair, Centre d'Études
Noël Mailloux,

12:00 - 13:30 **Lunch** (provided)

Poster-session

Beginning at 12:30

13:30 - 15:00 **Plenary session**

Janet Storch, Director, School of Nursing,
University of Victoria ; Chair, National
Council on Ethics in Human Research
Francine Saillant, Département
d'anthropologie, Université Laval
Hubert Marcoux, MD, Faculté de médecine
Université Laval

15:00 - 15:30 **Break**

15:30 - 17:30 **Concurrent Sessions**

Symposium

*Working Conditions and Professionalization of
Bioethics*

Chair: Dr. Georges C. Webster, St. Boniface
General Hospital, Winnipeg

20:00 - 21:00 **Visit to the Exhibition "Métissages" by
Robert Lepage and Reception at the Musée
de la Civilisation**

SATURDAY 21 OCTOBER 2000

7:30 - 8:30 **Registration/Breakfast** (provided)

8:30 - 10:00 **Plenary Session**

Technologies and Increase in Health Costs

Daniel Callahan, Director, International
Programs, The Hasting Center, (N.Y.), USA
Pierre-André Contandriopoulos,
Département d'économie de la santé,
Université de Montréal

Colleen Flood, Faculty of Law,
University of Toronto

Renaldo N. Battista, Chair, Conseil d'évaluation
des technologies de la santé, Québec

10:00 - 10:30 **Break**

10:30 - 12:00 **Concurrent Sessions**

Symposium

*Expensive Drugs: Can Ethical Criteria be the
Basis of Choices?*

Chair, Hubert Doucet, Faculté de médecine,
Université de Montréal

12:00 - 14:00 **CBS Annual General Meeting**

(lunch provided)

14:00 - 15:30 **Powerlessness of the Regulation?**

Workshops

Symposium

At the Crossroads: Ethics, Politics and the Law

Eric Meslin, Executive Director, National
Bioethics Advisory Commission, USA

15:30 - 15:45 **Break**

15:45 - 16:45 **Keynote Speaker**

Riccardo Petrella, Chair,

Université européenne de l'environnement

16:45 - 17:30 **Closing Remarks**

SUNDAY, OCTOBER 22, 2000

Post-Conference

Ethical Issues in Clinical and Social Research

8:30 - 10:00 *Ethical Issues in Social Research*

10:00 - 10:30 **Break**

10:30 - 12:00 *Ethical Issues in Social Research (ctd)*

12:00 - 14:00 **Lunch**

14:00 - 15:30 *REB and Clinical Research Follow-up (ctd)*

15:30 - 15:45 **Break**

REB and Clinical Research Follow-up (ctd)

**Hosted by: The National Council on Ethics in Human
Research (NCERH)**

12th Annual Canadian Bioethics Society Conference

October 19-22, 2000 • Quebec Hilton – Quebec City, Quebec

REGISTRATION FORM

ADVANCES IN MEDICINE: THE FALL OF HUMANISM?

To register: Complete and return
this Form by mail or by Fax to:

Secrétariat du Colloque de la SCB
(2000)
AGORA Communication
2600, Boul Laurier
Tour Belle Cour, bureau 2680
Sainte-Foy, (Québec)
G1V 4M6
Telephone: 418 658-6755
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http://www.ftsr.ulaval.ca/~scb2000

Note: To receive a confirmation of registration notice, your fax number must be provided

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City _____		Province/State _____		Postal Code _____
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CBS Membership (Sept. 2000 – Aug. 2001)

Regular	<input type="checkbox"/> \$60	Student	<input type="checkbox"/> \$35
Unemployed	<input type="checkbox"/> \$35	Eméritus	<input type="checkbox"/> \$30
Institutional Member	<input type="checkbox"/> \$200		

Pre-Conference (October 19)

Ethics and Psychiatry

CBS Regular Member	<input type="checkbox"/> \$60	<input type="checkbox"/> \$80
Student, CBS Member	<input type="checkbox"/> \$20	<input type="checkbox"/> \$20
Non Member	<input type="checkbox"/> \$75	<input type="checkbox"/> \$100

CBS 2000 Conference

CBS Member	<input type="checkbox"/> \$250	<input type="checkbox"/> \$285
Full Non-CBS Member	<input type="checkbox"/> \$350	<input type="checkbox"/> \$385
Full Student CBS Member	<input type="checkbox"/> \$90	<input type="checkbox"/> \$110
Full Student Non-CBS Member	<input type="checkbox"/> \$110	<input type="checkbox"/> \$125
Single Day Rate CBS Member		
Friday	<input type="checkbox"/> \$140	<input type="checkbox"/> \$180
Saturday	<input type="checkbox"/> \$140	<input type="checkbox"/> \$180
Single Day Rate, Non-CBS Member		
Friday	<input type="checkbox"/> \$180	<input type="checkbox"/> \$190
Saturday	<input type="checkbox"/> \$180	<input type="checkbox"/> \$190

Post-Conference (October 22)

CBS Regular member	<input type="checkbox"/> \$60	<input type="checkbox"/> \$80
Student, CBS member	<input type="checkbox"/> \$20	<input type="checkbox"/> \$20
Non-member	<input type="checkbox"/> \$75	<input type="checkbox"/> \$100
Half- Day Rate, CBS Member	<input type="checkbox"/> \$30	<input type="checkbox"/> \$40
Half Day Rate, Non-CBS Member	<input type="checkbox"/> \$40	<input type="checkbox"/> \$50

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Rates include collected abstracts, opening reception, and continental breakfast and lunch on Friday and Saturday.

A \$60.00 administration fee will be applied to cancellations made in writing up to and including October 15, 2000. After this date no refunds will be issued. Substitutions, however, will be accepted at any time in writing only.



Student Representative Report

By *Chris MacDonald*

Chris MacDonald

The time is upon us to submit abstracts for this year's Annual Meeting, to be held in Québec City in October. I hope that many of you students will submit something, and that those of you who hold faculty positions will encourage your students to do so. The CBS Annual Meeting is a congenial, multi-disciplinary event. I know many students are hesitant to submit something to a national conference. But you've got to start sometime.

Students would be well advised to get someone more senior to read a draft of their abstract well before the submission date. Writing an abstract is not an easy thing. As a former member of the Student Abstract Adjudication Committee, I know that the quality of abstracts varies enormously. Given that the CBS is a multi-disciplinary organization, and given that different academic disciplines have different ways of writing abstracts, it's no surprise that the abstracts submitted vary a lot. But one piece of general advice is possible: make sure that your abstract gives a clear idea not just of the topic you will cover, but how you propose to go about covering it. Give the adjudicators enough information to convince them that you can actually carry through on the promises your abstract makes.

One further note about submitting abstracts. I know that in past years, some students have avoided submitting abstracts because they thought that their abstract had to

conform to the "theme" of the conference. (Indeed, once upon a time, submissions to the student abstract competition were judged, in part, according to whether they fit with that year's theme.) For three years in a row, the students at the Student Luncheon held at the Annual Meeting have agreed that that would be an inappropriate criterion by which to judge student abstracts. The general feeling (among more senior folks I've talked to, too) is that students should be encouraged to submit their best work, not work that's been shaped or slanted to fit a yearly theme. This year, abstracts will be judged on their own merit, independent of the conference theme. So no matter where your work is situated within the spectrum of bioethics, you should feel free to submit something for this year's Annual Meeting.

I look forward to seeing you all in Québec. In the meantime, if you have any concerns about student issues, about the role of students within the CBS, or the role of students at the Annual Meeting, please feel free to contact me.

Chris MacDonald is currently a Post-Doctoral Fellow in Dalhousie University's Department of Bioethics. He serves on the CBS Executive Committee as Member-at-Large for the Atlantic Region, and in addition represents the interests of Student Members.

<chris.macdonald@dal.ca>



*Just a
reminder...*

CBS ANNUAL MEETING

will be held

October 11, 12, 13, 2001

Lombard Hotel

Winnipeg, Manitoba

Watch for details.



Aspirations and Observations from an Embryonic Ethicist

By Eoin Connolly

Eoin Connolly

In this article I will attempt to convey some of my impressions concerning the profession of bioethics from the standpoint of an undergraduate student entering the field. The future of becoming an ethicist greatly excites me but also fills me with trepidation. I understand ethicists are called upon to aid in the decision making process of others in some of the most sensitive issues: life, death, and reproduction. Ethicists are asked to inform, explain, and guide others towards the moral truth for which those in a situation search. Government, scientists, physicians, patients and families in some cases request assistance from ethicists to help them resolve issues involving allocation of resources, treatment options, and whether or not to prolong life or let nature take its course. Often, I wonder whether or not I will acquire the education and experience that I think will properly prepare me for this profession.

As an undergraduate student at the University of Toronto preparation for the work of ethicists takes place through lectures, course readings, various seminars, conferences and workshops. Now, students can only learn so much from this type of learning. Experience is also required both in the academic and clinical settings. For example, it has recently been suggested that an undergraduate bioethics society and e-journal should and will be started at the University of Toronto. This would allow for students to learn to express their ideas to their peers and have it critically reviewed. There is also a need for students to be exposed to the clinical setting. For example, students should be able to sit in on REB's or job shadow in a clinical setting. This type of experience would also allow students to realize the difference between theory and practice and the difficulties associated with principles learned within the university and their application in the clinical setting. This type of experience cannot be taught in an academic setting but nevertheless is an essential element to the training of an ethicist. I am aware of a number of opportunities in the United States offering internship programs to students interested in bioethics at the undergraduate level. Could this be emphasized more in Canada?

Heroes of Bioethics

In his article, *Where are the Heroes of Bioethics?*, Benjamin Freedman suggests that he is unaware of a case where an ethicist had lost his or her job for taking a principled stance. He does not suggest that a conflict of interest

between an ethicist and another party do not take place but rather that an ethicist may give in and conform to the assessment of the opposing party. Recently, however, ethicists have lost their jobs based on a principled stance. From my perspective it is evident that conflicts of interest exist between ethicists and hospital administration. In such cases, hospital administration can threaten termination of employment. These cases may linger in the minds of some ethicists creating a great deal of pressure to conform and "to be a team player".¹ A community climate needs to be created where the acts of heroism, as defined by Freedman, are not required. This is not to suggest a uniformity of ideas but rather a setting in which conflicts of interest are negated and differences of opinion are seen as productive in the pursuit of an appropriate decision. Moreover, there is a need for some sort of policy where ethicists can be protected but at the same time be held accountable for their performance. This would then allow for the ethicist to openly express his/her views and not fear the consequences. Maybe the solution is a form of union or association where the ethicist would be appointed by the members of a governing body rather than hired by a hospital. The union could then be guided by some form of bioethics community standard, where a range of views are held to be acceptable. Conflicts would then be resolved based on these ethical community standards and not private interests of the hospital or the individual ethicist.

Conclusion

Ethicists presently play an important role in society and their role will most likely grow with time. Therefore young ethicists need as much exposure as possible to the various settings in which they might be placed. In order to do this embryonic ethicists need opportunities. The only ones that can provide these opportunities and lead young ethicists are practicing ethicists. Undergraduate students must be allowed and encouraged to seize knowledge of the various interpersonal relationships and conflicts that constitute the clinical setting and therefore becoming better prepared to meet the daily challenges of a ethicist.

NOTES

¹ Baylis, Francoise E., ed. "A profile of the Health Care Ethics Consultant" in *The Health Care Ethics Consultant*. Totowa NJ: Humana Press.

Eoin Connolly is an undergraduate student at the University of Toronto majoring in Bioethics. <e.connolly@utoronto.ca>

Surviving the Gender High Wire Act: Young Women's Sense of Their Experiences in Science on Campus and in the Workplace

By Nancy Johnson Smith

Although the numbers of women entering science have substantially increased, women still experience much higher rates of marginalization and attrition than do men (Eisenhart & Finkel, 1998; Keller & Longino, 1996; Rhode, 1997; Stalker & Prentice, 1998; Valian, 1998). Indeed, the journal *Nature* recently held an internet debate engaging scholars of both genders to address this problem. As a result of such investigations, an awareness is emerging that the obstacles to women's full participation in science stem largely from the traditional male-associated practices and culture of science itself, for example, the conflicts between the traditional female "nurturing" role and the male work pattern demanding "110%" career commitment and the widespread denial of opportunities to acquire crucial skills, experience, mentoring and female role models. All these have resulted in accumulated disadvantages, leading to the present vertical segregation of the genders in the sciences.

To help understand the changes needed for women to survive, even thrive, in such a climate I have initiated a longitudinal interview study which includes 16 women in a range of basic and applied science fields. My goal is to explore how they describe their negotiation of the above noted practices during undergraduate training and subsequent graduate and workplace experiences. Using a discursive approach (Potter & Wetherell, 1987), I examine the shifting interpretive resource/strategies they employ to make sense of their experiences and the likely implications, positive and negative, of these interpretations for their careers.

The first interviews took place in 1994-95, when the interviewees were 20 to 23 and in their last two years of university. Unlike most participants in earlier studies they expressed little need to compromise career plans for marriage or romantic roles yet they also expressed an unwillingness to sacrifice time with friends or family despite the competition for grades they described. Thus their accounts suggested they had avoided the double bind women tend to experience in educational contexts

previously set up for men: feeling that a woman can only win male acceptance in professional terms by denying a sense of herself as female, with a need for connection and support (Seymour, 1995).

What I found particularly interesting, however, were the views not expressed. First, they did not identify as gender-disadvantaged, e.g., anticipating a career glass ceiling, nor did they value women's support organizations. Instead, their accounts drew heavily on the discourse of individualism: if you try hard and do good work, you will succeed, but if you fail, it 's your own fault. Thus despite their expressed self-confidence, these interviews raised questions about how the women would interpret future job or family-related difficulties—as an indication of constraints on women in a male-dominated system, or, as personal inadequacy?

"Such sense-making reflects the discourse of gender neutrality that permeates most workplaces today, which assumes that both genders are treated fairly and that any problems suggesting the contrary are due to individual inadequacy."

In 1999, to answer this question, I re-interviewed the same women to ask what had happened since we'd last talked. I critically looked at what they seemed to take for granted, e.g., that personal agency should overcome any difficulty. I also examined discontinuities and contradictions in their talk, which are expressions of resistance and struggle which can allow new ideas to emerge about more empowering ways women can perceive their choices.

In some ways their accounts had not changed; in other ways they indicated the women were "getting clued in," as one interviewee phrased it. They continued to assert their competence in their fields and their right, even obligation, to establish careers. At the same time, most also described a new awareness of both differential treatment for the genders and isolation from female colleagues. Contradictions particularly arose in talk about parenthood plans. Here they still struggled to reconcile the expectations for achievement placed on both genders today and those persisting for the traditional "good daughter, wife and mother. However, all used a range of discursive strategies to resist identifying such difficulties as due to

... continued on page 8

discrimination and unequal gender power relations, i.e., as part of a system of structural inequality. Most implied that they, unlike other women, recognized that fitting in was a matter of eventually learning the rules. Such sense-making reflects the discourse of gender neutrality that permeates most workplaces today, which assumes that both genders are treated fairly and that any problems suggesting the contrary are due to individual inadequacy.

In conclusion, I find reason for optimism about women's future in the sciences from these women's ability to

provide life accounts that generally convey competence and self-confidence. However, if women are to participate as equals to men in science and technology, the findings also suggest they need to be made much more aware of the cultural contexts and gender myths that still place them at a disadvantage in and constrain their ability to act for needed change.

Nancy Smith works at the University of Calgary. This project was supported by a grant from the Canadian Research Institute for the Advancement of Women (CRIAW).

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SELECTED REFERENCES:

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- Nancy Smith works at the University of Calgary. This project was supported by a grant from the Canadian Research Institute for the Advancement of Women (CRIAW).



Jane Cawthorne

Assessing New Reproductive and Genetic Technology As If Children Mattered

By Jane Cawthorne

A significant rationale for our collective investment in new reproductive and genetic technologies (NRGTs) is often the unquestioned assumption that we value children. To the promoters of this work, the promise of a child looms large as a mediating factor in its evaluation. The end justifies the means. The measures may be "heroic," but since the result is a baby, they are deemed to be worth the effort. However, current assessments of NRGTs generally gloss over their impact on children, excluding them from something in which they are profoundly implicated. It is time to remedy this failing.

There are significant barriers to constructing a discourse around NRGTs with children at the centre. This is particularly true for feminists who have resisted highlighting the interests of children because of the way in which the rights of the child are often invoked to control women in reproduction. In medicalized childbirth, the woman and fetus are understood as antagonistic and the

actions of the mother must be monitored to protect the fetus. To bring children in from the periphery of the discourse, we need to abandon this kind of thinking and understand pregnancy in holistic terms which appreciate its unity. A more useful metaphor is that pregnancy is like a prime number. Different digits add to its total, but it is indivisible by anything other than itself and one. It is difficult to imagine antagonism in a unified whole.

Another barrier to constructing this discourse is the difficulty of speaking for children, particularly those that are not even born yet and possibly not even conceived. There are models that we use when we speak for children such as trusteeship or proxy consent. Such models are entirely consistent with a holistic notion of pregnancy and a general paradigm that recognizes the interests of people as interconnected. However, it is equally problematic to suggest that the interests of mother and child are the same as it is to suggest they are antagonistic. Generally, when feminists do consider the interests of children, we assume

that what is good for the goose is good for the gosling and if conflict arises, the goose comes first. This approach disrespects the child, just as asserting fetal rights without supporting the woman disrespects the woman. Proxy consent can become a “warrant for abuse” when we assume we know the needs of others but are wrong, misguided, or ill-intentioned. (Ignatieff, 1985:11)

This happens easily enough. Just as we often deceive ourselves about our true needs, it is easy to make mistakes about the needs of others. For example, I might desperately want a child. In order to serve my desire, often expressed as a need and sometimes as a right, I access some form of NRG. But I cannot know it is in the interest of an unconceived child to be, specifically, *my* child. In other words, an intense desire for a child does not correspond to a child’s desire to *be* a child. This situation, unlike others, is not a good one on which to base proxy consent. In this case, I am really speaking about self-interest. Proxy consent has its limits. No one asks to be born.

To compound the problem, the emphasis when considering NRGs has always been on producing a child, or on the physical body itself. This emphasis favours a notion of a child as a product rather than a social or spiritual entity. All that matters is that it is alive. It is worth noting that even if our arguments on behalf of children were to focus solely on the physical body, there is indeed reason to be concerned about the impact of NRGs. For some time now there has been enough information in the scientific literature to encourage us to give the impact of NRGs on the bodies of children a more central place in the discourse. For example, some researchers find that using in-vitro fertilization, there are higher rates of spontaneous abortion, ectopic pregnancies, pre-term delivery, low birth-weight and birth defects. (Overall, 1993; Rothman, 1994)

REFERENCES

Ignatieff, Michael. 1985. *The Needs of Strangers*. New York: Elisabeth Sifton Books/Viking.
 Overall, Christine. 1993. *Human Reproduction: Principles, Practices & Policies*. Toronto: Oxford University Press.
 Rothman, Barbara Katz. 1994. “Reproductive Technologies Offer False Hope and Serious Risks.” In O’Neill, Terry ed., *Biomedical Ethics: Opposing Viewpoints*. San Diego, Greenhaven Press.

However, there is more to a child than a body. We must consider the mind and spirit as well as the body. Fundamental human questions like “where did I come from?” will be asked by a child at some point in his or her life. It is clear that with many NRGs, parentage can become quite confusing. Genealogical bewilderment may well contribute to some negative psycho-social or emotional effect, yet there has been no long-term study to explore this issue.

In addition, feminist critics have long argued that NRGs treat people like commodities. As disastrous as this thinking is for women, it is even moreso for children. Combining the technologies of IVF and prenatal genetic testing, we can (and already do) create children according to our desires. But a person is not a manufactured item who can be assessed on a scale of one to ten according to the strict guidelines of quality control. A child’s presence cannot be conditional on their genetic endowment, their health, their mood, their behaviour, their sex, the colour of their skin, their ability or anything other than the fact of their existence. When the presence of children becomes conditional, we leave them spiritually impoverished.

Too often with NRGs, children are the bait and just as we do not consider the interests of the worm when we go fishing, this kind of approach does not consider the interests of the child. Just as women must be central to any assessment of NRGs and not be objectified by it, so must children. Focussing on children is a necessary step towards a more thorough assessment of new reproductive and genetic technologies and must become a priority.

Jane Cawthorne is a mother, writer, activist, and educator living in Calgary, Alberta. She is also currently a Trustee for the Calgary Board of Education.

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José Roberto Goldim

Bioethics and Informed Consent in Brazil: What Are They Good For?

By José Roberto Goldim

Bioethics as a formal discipline is a recent notion in Brazil. Evidence for this can be found in the way informed consent is used in this country in research involving human beings.

In 1981, the Brazilian Department of Health created the "Risk Knowledge Form," which became an official requirement for all research projects with experimental, non-registered drugs. As can be gathered from the very name given to this instrument, its objective was merely to *inform* participants about the experimental character of the drug being tested. In case of harm resulting from research, the form placed all responsibility on the researcher and on the research funding source, and exempted the Department of Health entirely. There was no mention either to criteria regarding the individual's ability to consent or to the need to address specific risks of each particular drug being tested. The proposed text was very broad. It made no reference to issues relative to the understanding of its contents and to the voluntary character of participation in research. The only concern was to register the redistribution of certain types of information.

The first official document to propose the formal application of informed consent in Brazil was issued in 1988. This document established what became the Official Guidelines for Biomedical Research in Brazil. In 1996, these guidelines were revised. The revision ended up being a retrogression, since, according to the new text, children lost the right to take part in the process of consent. This was, in part, corrected in 1997, when specific guidelines were established for research involving new drugs and vaccines.

Hospital de Clínicas de Porto Alegre (HCPA) is a 745-bed university hospital, affiliated with the Federal University of Rio Grande do Sul. It serves as a teaching and research institution for the University's medical school, as well as for post-graduate courses in medicine and other health-related fields. HCPA has an Ethics Committee since 1974; when it was created, this Committee analyzed a few research projects every year. The Committee underwent a restructuring in 1989, and became the Graduate Research Group, an office that helps researchers organize their projects, and that analyzes and follows the execution of

projects approved to be carried out in the Institution. In 1994, a Research Ethics Committee was created to act along a Scientific Committee, both inside the Graduate Research Group.

Looking at data from 1,587 projects that were analyzed (approved for execution or not) at HCPA between 1987 and 1997, it is possible to get a few interesting insights. Only 33% of the projects mentioned informed consent the first time they were submitted to the Ethics Committee. Among the projects that mentioned informed consent, 38% had inadequate consent forms that neither described the risks and benefits for research participants, nor the right of participants to privacy and confidentiality. Around 18% of the forms were written using technical jargon not necessarily accessible to study participants. These data show that Brazilian researchers are not yet prepared to elaborate informed consent forms. Many times, for example in the case of multicenter international studies, the forms submitted to us are literal translations of the original informed consent form written in a foreign language different than Portuguese.

We are currently carrying out a study to analyze the structure of informed consent forms according to the Flesch-Kincaid Scale. All the forms being analyzed were considered acceptable by the Research Ethics Committee at HCPA. So far, all the forms scored more than 12 points in the Flesch-Kincaid Scale, that is, approximately 12 years of schooling would be required for full understanding of the text by a study participant. Most patients have only 5 to 8 years of schooling.

The data available suggest that there is much work still to be done regarding informed consent in Brazil. Informed consent is seen by researchers much more as a legal requirement than as a tool to ensure respect. It is necessary to make investments in qualifying researchers and to emphasize ethics as a major part of the education of future researchers. If that is not done, Informed Consent will become synonymous with Exemption of Accountability, and will end up serving the opposite end to which it was created.

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Canadian Institutes of Health Research: A new idea, a new resource

By Patricia Kosseim

Effective June 7, 2000, the Canadian Institutes of Health Research (CIHR) (www.cihr.ca) was created by legislation to excel in the creation of new knowledge and the translation of that knowledge into improved health for Canadians, more effective health services and a strengthened Canadian health care system.

In meeting this objective, CIHR is committed to:

- promoting, assisting and undertaking health research that meets the highest standards of ethics;
- fostering the discussion of ethical issues and the application of ethical principles to health research;
- monitoring, analysing and evaluating ethical issues pertaining to health or health research;
- encouraging inter-disciplinary, innovative and integrative research on ethical issues pertaining to health.

An important ethical, legal and social issue currently being debated by federal, provincial and territorial policy-makers is how best to respect the interests of Canadians in keeping their personal information private, while also enabling access to that information to better the health of the population, improve health care services and maintain a sustainable health care system. In this context, CIHR has recently published *A Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research*.

This Compendium is specifically designed to provide users with a panoramic view of the legislative landscape

across the country. It contains relevant excerpts of existing and draft Canadian legislation, both federal and provincial, respecting the right to privacy and data protection principles applicable to health research. The legislation is further sub-divided, in some cases, between public and private sectors, general and sectoral statutes specific to the health sector. Organized by theme, each chapter allows comparisons to be drawn across different jurisdictions and certain trends to be deduced. Finally, the Compendium also contains relevant ethical norms governing the responsibility of health researchers to respect the privacy of research subjects.

It is hoped that this Compendium will serve:

- as an information tool for providing direct and convenient access to existing and developing legislation in this area;
- as a communication tool to facilitate dialogue between stakeholders in the current privacy debate; and
- as a working tool for legislators and policy-makers as they consider the development of a harmonized policy framework respecting the protection of personal information in the health sector.

Copies of the *"Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research"* can be obtained by contacting Ms. Sophie Ouellette at (613) 946 4773 or souellette@cihr.ca.

Patricia Kosseim, CIHR, Senior Ethics Policy Advisor
<pkosseim@cihr.ca>

CBS Newsletter

The Canadian Bioethics Society was founded in 1988. It seeks to 1) bring together persons and organisations concerned and involved in bioethics; 2) forge links between them, and provide a forum for the exchange of views and ideas; 3) assist in solving the problems of daily practice, and; 4) develop long term solutions to broader social questions. To help achieve these goals the Canadian Bioethics Society (CBS) publishes a newsletter. The newsletter was created to promote more effective communication between society members. It serves to inform members about news from the society, the Annual Conference and current ethical issues facing Canadians. Submissions should be sent to Paula Chidwick, Editor at pchidwic@uoguelph.ca in WordPerfect 5.1 or Richtext Format.

Candidates for 2000-2001

Members-at-Large:

Atlantic — Mr. C. MacDonald

Chris MacDonald recently completed his Ph.D. in Philosophy at the University of British Columbia, and is a Graduate Research Associate at the UBC Centre for Applied Ethics. His M.A. Thesis (1994) discussed professional ethics and the limitations of risk assessment. His Ph.D. Dissertation was entitled "The Moral Significance of Social Conventions." His most recent work in health care ethics has covered such topics as: working conditions for medical Residents; the way standards of practice structure clinical ethical decision-making; issues of autonomy in the treatment of eating disorders; and implications of multidisciplinary health care for safeguarding patient rights.

Chris MacDonald also currently serves on the Ethics Steering Committee of the BC Cancer Agency's Vancouver Cancer Centre. He designed and maintains the Centre for Applied Ethics award winning web-site, one of the top applied ethics web-site in the world.

He has been an active member of the CBS since 1994, and also designed and maintains the CBS web-site.

Eastern — Dr. K. Glass

Central — Dr. J. Nisker

Jeff is a Professor of Obstetrics and Gynaecology and coordinator of bioethics at the University of Western Ontario. Jeff is co-chair of Health Canada's Advisory Committee on Reproductive and Genetic Technologies and a member of the National Council of Ethics in Human Research. He is currently a member of the Canadian Bioethics Society Council. Jeff's past national positions include Health Canada's Advisory Committee on Embryo Research, national director of the Society of Obstetricians and Gynaecologists of Canada (SOGC) and an author of the International Federation of Fertility Societies *Ethical Guidelines*. Jeff is the new Editor-in-Chief for the *Journal SOGC*.

Jeff received his undergraduate and medical education at the University of Toronto, and his training in obstetrics and gynaecology at U.W.O. He was awarded a Medical Research Council of Canada Fellowship in hormones and cancer and did post-doctoral training at U.W.O., University of California, and McMaster University.

Jeff has written many scientific articles and book chapters. He has written six plays surfacing issues from woman abuse to HIV to genetic essentialism. He has also written many short stories and poems to encourage his "compassion in health care." His plays have been per-

formed throughout Canada and the United States. In 1996 Jeff received the Douglas Bocking Award presented to the U.W.O. "member of Faculty who, in the opinion of medical students has made the most outstanding contribution to their medical education during the previous four years."

Western — Dr. K. Oberle

Kathleen Oberle is currently an Associate Professor at the Faculty of Nursing, University of Calgary, where she has been for the past 7 years. Her interests in ethics include clinical decision making and research ethics. Following those interests, she teaches a graduate course in research ethics, is a member of two research ethics committees and the Research Ethics Policy Committee at the U of C, and teaches ethics in a variety of nursing courses. She has conducted several studies on ethical decision making in health care, has made numerous presentations at local, national, and international levels, and until recently served as ethics consultant to the Alberta Children's Hospital. She has been an active member of the CBS since 1990, and has served on the association in several capacities: as Western representative of the advisory committee for two years, as member of the 1999 conference planning committee, and as member-at-large for two years.

Student Rep:

No Student representative for this year

Treasurer:

Michael Coughlin

Michael Coughlin is Ethics Consultant at St. Joseph's Hospital in Hamilton and Associate Professor of Psychiatry and Behavioural Neurosciences at McMaster University. He received his undergraduate degree in Philosophy from the University of Notre Dame, completed a Licentiate in Theology at the Catholic University of Chile, obtained his Doctorate in Developmental Biology from Stanford University, and has held faculty positions at the New York Hospital/Cornell Medical College and at McMaster University. Dr. Coughlin initiated the position of Ethics Consultant at St. Joseph's Hospital in Hamilton and continues to work there and with other institutions of the St. Joseph's Health System. He has contributed to organizing ethics education in the Faculty of Health Sciences at McMaster and has published studies on ethics consultation in Canada. Michael has been actively involved with the CBS since its inception. He worked on organizing committees for two annual meetings and was a member of the Executive from 1993 to 1998, serving as President for the 96/97 term.



Chris MacDonald

Organizational Ethics: Innovative Collaboration at Dalhousie

By Chris MacDonald

The term “organizational ethics” is increasingly salient in bioethics, as well as in a range of other contexts. A significant component of Canada’s contribution to this burgeoning field comes from a unique set of interconnected collaborative ventures currently underway at Dalhousie University in Halifax.

This project has at its core a collaborative venture between Dalhousie’s Department of Bioethics (led by Dr. Nuala Kenny) and Health Law Institute (led by Dr. Jocelyn Downie). This collaboration has as its primary goal the investigation of the relationships between values, policies, and practices in health and health care. This interest in values and policies inevitably leads to an interest in the ethical analysis of the values embedded in the behaviour of organizations.

The Dalhousie Collaboration has two main branches. The first branch links the Bioethics/Health-Law collaboration with Dalhousie’s three major academic health centres. This aspect of the collaboration is being co-ordinated by Carolyn Ells. Ells, currently completing her Doctoral Dissertation through the University of Tennessee, brings to this venture both clinical experience (as a Respiratory Therapist) and philosopher’s affinity for conceptual analysis. The first step in this aspect of the Collaboration was the completion of a formal survey-based needs-assessment process. The results of this needs-assessment are helping the partners in this project to establish priorities and chart a course for future educational and policy-development activities. One of the unique aspects of this collaboration with the hospitals is that no ethics case-consultation is involved. The goal here is rather to help healthcare organizations grapple with ethically significant questions that permeate all aspects of institutional life.

The second branch of the Collaboration brings together the Department of Bioethics and Health Law Institute with the Nova Scotia Department of Health. This branch of the collaboration is being co-ordinated by Chris MacDonald, Ph.D. This branch of the Collaboration has two main goals. The first is to assist policy-makers at the Department of Health in clarifying the value/ethics aspects of pressing issues in health policy. This sort of direct interaction between ethicists and policy makers is long overdue. The second goal of the project is to engage in academic reflection on the role of values in health policy-making. This reflective process has tremendous potential to allow the broader academic and policy-making communities to benefit from what is learned through this unique interaction of health policy makers and academic bioethicists.

The first pieces of academic reflection to come out of the Dalhousie Collaboration include an article by Kenny, Downie, Ells, and MacDonald (“Organizational Ethics Canadian Style”) in HEC Forum (Vol. 10, No. 2, June 2000), a poster by Kenny and Downie (“Organizational Ethics and Health Policy: A Canadian Model”) presented at ASBH 1999, and a poster by MacDonald and Ells (“Organisational Ethics, Business Ethics, and Health Care: Framing Policy at the Institutional Level”) presented at the Values in Health Policy conference being held at McMaster University in May.

Hopes are high, in Halifax, that this innovative collaboration – involving philosophers, clinicians, legal scholars, hospital administrators and government policy-makers – will prove to be enormously fruitful in its own right, and that it will also serve as an exemplar of a new and exciting kind of work in bioethics.

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The Canadian Bioethics Society
has its own page on the World Wide Web!

Check out the site at

<http://www.bioethics.ca>



*“Medicine, technology and humanism:
an alliance against nature?”*

12th ANNUAL CANADIAN BIOETHICS SOCIETY MEETING

*will be in Quebec City, Quebec at the Quebec Hilton on
October 19-22, 2000*

For more information contact:

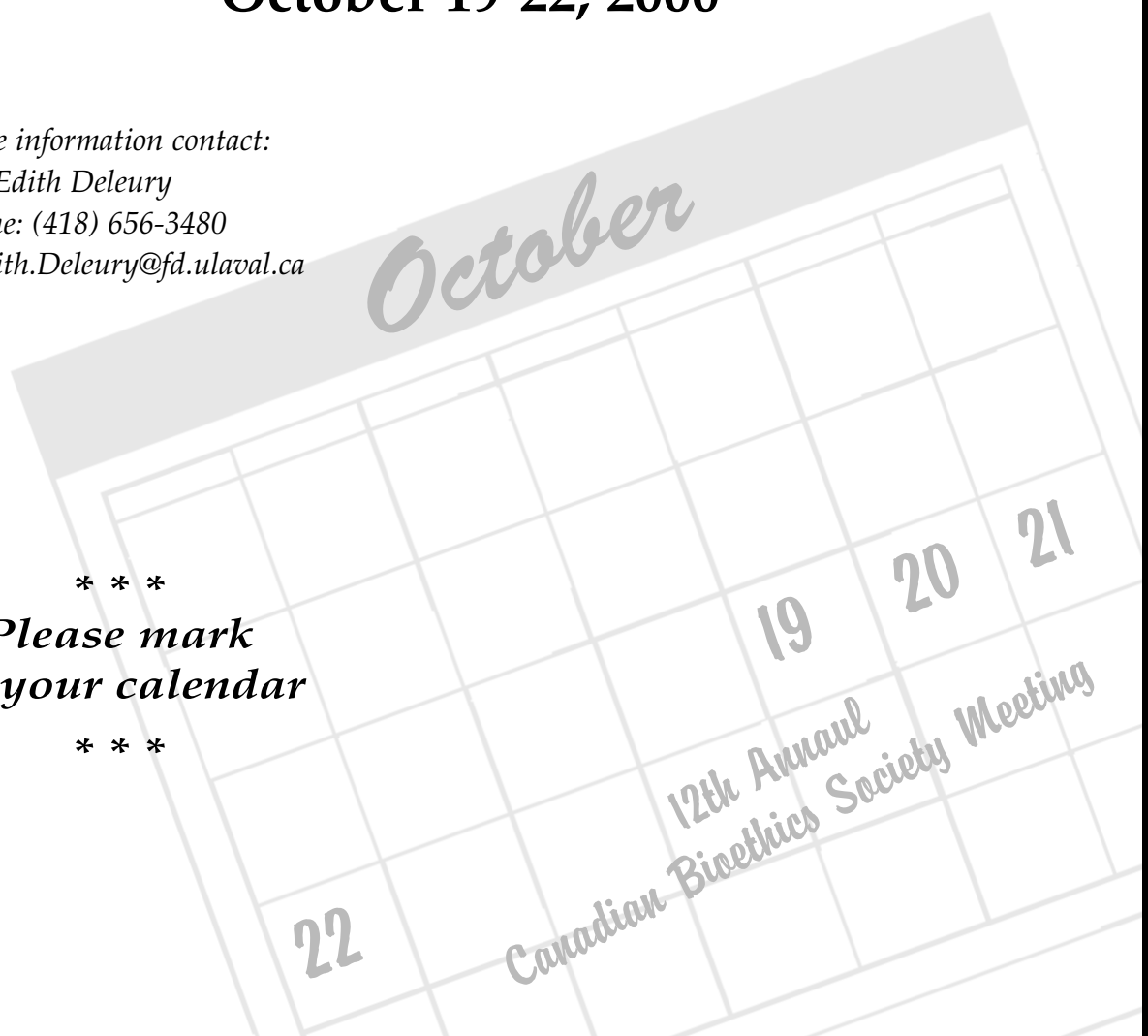
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** * **
Please mark
on your calendar

** * **



REPORT ON RAPID TESTING NOW AVAILABLE

In March 2000, Health Canada approved the first rapid HIV test for use in Canada. The Canadian HIV/AIDS Legal Network has prepared an in-depth analysis of the potential benefits of rapid point-of-care testing, and of the concerns raised by the use of such tests.

“Rapid HIV Screening at the Point of Care: Legal and Ethical Questions” includes an executive summary and over 20 recommendations to ensure the potential benefits of rapid point-of-care testing are maximized, while the potential harms are minimized. The report also includes an accompanying ethical commentary on the issues.

The full report can be downloaded now in English and in French from the Network’s website at
<<http://www.aidslaw.ca>>.

Look under “Added in March 2000” on the home page.

As of mid-April 2000, hard copies of the report can be obtained from the
Canadian AIDS Clearinghouse, 1565 Carling Avenue, Suite 400, Ottawa ON, K1Z 8R1.

Tel.: (877) 999-7740 (toll-free) or (613) 725-3434.

Fax: (613) 725-1205. E-Mail: <aids/sida@cpha.ca>.

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