Canadian Bioethics Society
NEWSLETTER
Volume 4, Number 2 August 1999

President's Letter
Thérèse Leroux 1998-1999

This year, due to financial constraints facing the Canadian Bioethics Society, the Executive Committee has decided to publish only two issues of the Newsletter. Hence, this is the second and last letter I will be writing to you as President. Be assured, however, that any developments occuring after the publication of this Newsletter will be made known to you during the next Annual Meeting, to which you are cordially invited.

During the past few months, the Executive Committee has been working on amendments to the Constitution and By-laws of the Canadian Bioethics Society. You will find the most recent revised version in this newsletter.

This task of reviewing and rewriting is the outcome of one of the decisions made during the Annual Meeting in Toronto last year. At that time, the members present adopted the recommendations proposed by the Working Group on Governance, concerning the administrative structure of the Society. The Executive Committee simply inserted these changes into the Society's Constitution and By-Laws document. The modifications made to the text had been previously approved. Allow me to mention a few of these changes. Beginning in the year 2000, the Advisory Council will no longer exist. However, regional representation, a fundamental — even vital — characteristic of the Society, will be maintained. In fact, the Executive Committee will include four Members-At-Large, one from each of the geographical regions defined by the Society (Atlantic, East, Centre, West). Furthermore, in recognition of the important contribution made to the CBS by students, a position exclusively for students has been created within the Executive. While maintaining a size that favors communication, this new structure will surely allow the Society to benefit from the expertise and enthousiasm of its members. The mandates for each of the members of the Executive Committee has been lengthened to allow these elected representatives sufficient time to complete their projects. Finally, a new committee, the Finance Committee, has been created. This committee will certainly play a crucial role within the CBS, given the precarious financial situation of the Society. The revised version of the Canadian Bioethics Society's Constitution and By-Laws should receive approval during the next Annual Meeting in Edmonton.

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Canadian Bioethics Society
NEWSLETTER

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Marianne Lamb — President-Elect
Paula Chidwick — Communications Officer

Members-at-Large

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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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President's Letter *– continued from pg. 1 …*

Given the completion of this project, we may now address other topics of interest to members of the Society. Recent events within the scientific and medical communities have attracted our attention and incited us to question ourselves. For example, what responsibility does a research ethics committee and its members have when they are informed about undesirable side-effects within a test group? Or, what is the extent of freedom accorded to an ethicist who would like to pursue consultation during a complex case? Furthermore, what are the characteristics of a person «versed in ethics», given that research ethics committees require their presence? Is this person different from a bioethicist? How can we find answers to these questions, and many others?

The moment has no doubt come to consider the possibility of elaborating a Code of Ethics. What are your views on this issue? Some of you may think it more reasonable to prepare a statement of member's rights and responsibilities. The questions have been raised and we must now begin to reflect on this issue; the next annual conference will surely allow us to pursue this endeavor.

With this in mind, I invite you all to participate in the 11th Annual Canadian Bioethics Society Conference which will take place in Edmonton from October 28 to 30, 1999. I sincerely hope to have the pleasure of meeting you, and particularly request your presence at the Annual Meeting of the Canadian Bioethics Society on Saturday October 30. Your participation will contribute to furthering the development of the Canadian Bioethics Society.

leroux@droit.umontreal.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.

CBS Constitution and By-Laws

CONSTITUTION

***Article 1:** NAME*

The name of the organization shall be the Canadian Bioethics Society — Société canadienne de bioéthique.

***Article 2:** OBJECTIVES*

2.1 The Society shall be managed efficiently and democratically by an Executive Committee which is responsible to the general membership.

2.2 The Society's activities and structure shall reflect theoretical, policy and clinical levels of study and discussion of bioethics providing a forum for interested professionals to exchange ideas and address problems in bioethics. The Society shall promote the teaching of bioethics at all levels of undergraduate, post-graduate and continuing education. Research and publication in bioethics shall be encouraged as well as provision of ethics information for practicing professionals and for the general public.

2.3 The Society will be bilingual in nature and proceedings. Membership will be encouraged and welcomed from both English and French language groups; official documents of the Society will be prepared and provided in both English and French, and participants at meetings may speak in English or French.

2.4 The business of the Society shall be conducted without a purpose of gain for its members, and any profit or other accretion of the Society shall be used in promoting its objectives.

BY-LAWS

***Article 1:** MEMBERSHIP*

1.1 The Society shall consist of active members and honorary members.

1.2 New members of the Society shall be accepted subject to approval by the Executive Committee.

1.3 The Society is primarily for persons who have a significant involvement in teaching, research or clinical aspects of bioethics. Any person who is a registered member of a health care profession, or who has a university degree in fields related to ethics, bioethics, or law, or other interested persons, shall be eligible for active membership.

1.4 Bona fide students may apply for membership at a reduced annual fee.

1.5 The Executive Committee may revoke the membership of any Society member who fails to pay annual dues.

1.6 On the recommendation of any members, any individual may be proposed by the Executive Committee for election as an honorary member at the Annual Meeting. Honorary members are non-voting and pay no dues.

***Article 2:** EXECUTIVE COMMITTEE*

2.1 The Executive Committee derives its authority from the Constitution of the Society, and is charged with conducting the day-to-day business of the Society. Decisions made and other actions taken by the Executive Committee shall be reported to the members at the Annual Business Meeting of the Society.

2.2 The Executive Committee shall consist of the President, the President-Elect or the Past-President, the Secretary, four Members-at-Large (one from each of the four geographical regions), the Student-at-Large, the Treasurer, and the Communications Officer.

2.3 The President-Elect, Secretary, Members-at-Large, the Student-at-Large, Treasure and the Communications Officer shall be elected at that Annual Business Meeting of the Society relevant to the terms of their appointments.

2.4 Ordinarily, one person will serve, sequentially and consecutively, as President-Elect, President, and Past-President: the term of office for the President shall be two years; the terms of office for the President-Elect and the Past-President shall be one year each. The Secretary shall be elected to serve a three-year term. The four Members-at Large shall each be elected to serve two year terms, renewable once. The Student-at-Large shall be elected to serve a two-year term, renewable once. The Treasurer and the Communications Officer shall each be elected to a three-year terms, renewable once.

2.5 No person shall serve on the Executive Committee for more than six consecutive years.

2.6 The Executive Committee of the Society shall:

(a) Alternate the Presidency between professionals in health sciences and professionals in ethics or law.

(b) Have at least one Anglophone and one Francophone on the executive.

(c) Have at least two professionals in ethics, one of whom may be a lawyer and one of whom must be an “ethicist” (a professional employed to consult, research, or teach in bioethics, who has a doctorate in theology or philosophy).

(d) Have at least one physician.

(e) Have at least one nurse.

(f) Have at least one graduate student/resident member in one of the disciplines related to bioethics.

… continued on pg. 4

CBS Constitution and By-Laws*… continued from pg. 3*

(g) Have, in addition to the five specified requirements of c, d, e, and f, additional members forming not more than a ten-member Executive Committee.

Article 3: *DUES*

3.1 Society dues will be assessed annually in an amount proposed by the Executive Committee and approved by the Members.

Article 4: *COMMITTEES*

4.1 The Nominating Committee shall be appointed annually by the Executive Committee not later than January of each year. The Nominating Committee shall chaired by the immediate Past-President or the President-Elect and consist of four additional members, chosen so as to represent all four regions of the Society. Of the latter regional representatives, two shall not be current members of the Executive Committee. The Committee should include at least one clinical professional (e.g. a physician or nurse) and at least one non-clinical professional (e.g. a theologian, philosopher or lawyer).

4.2 The Program Committee shall consist of the President, President-Elect or Past-President, the Treasurer, and the Chairperson of the locally-selected Annual Meeting Committee, the latter person being an Active Member of the Society. The Program Committee shall organize and promote the various programs of the Society.

4.3 The Finance Committee shall consist of the Treasurer (Chairperson), the President, the President-Elect or the Past-President, one Member-at-Large of the Executive Committee and one representative of the general membership (preferably the Chairperson of the relevant local Annual Meeting Committee). The Finance Committee shall manage the finances of the Society and draft the annual budget.

Article 5: *MEETINGS*

5.1 The Society shall hold at least one meeting annually, at a time and place to be decided by the Executive Committee. The Executive Committee shall rotate the meeting site to give appropriate consideration to the four geographical regions.

A) **Western** — British Columbia, Alberta, Saskatchewan, Manitoba and the Territories
B) **Central** — Ontario
C) **Eastern** — Quebec
D) **Atlantic** — New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland

5.2 Notification of any Business meeting must be sent in writing to all Society members at least two months in advance.

5.3 At each Annual Meeting of the Society, a Business Meeting shall be held. At the Annual Business Meeting, the reports of the Committees of the Society shall be presented for information of the membership, and where necessary, for approval. The election of the new Members of the Executive Committee shall be held at the Annual Business Meeting. Election to the Executive Committee shall require a majority of the votes of the total number of active members present and voting and of active members who submitted mail-ballot votes, where the latter practice is in accordance with the Society's policies governing mail-ballot voting. The quorum for the Annual Business Meeting of the Society shall be twenty active members.

Article 6: *AMENDMENTS*

6.1 The Constitution and the By-Laws may be amended by a majority of two-thirds of those members present at an Annual Business Meeting of the Society.

6.2 Amendments to the Constitution or By-Laws must be proposed in writing to the Executive Committee by three active members.

6.3 Proposed amendments to the Constitution and By-Laws of the Society must be sent in writing to all members at least two months before the Annual Meeting at which the proposed amendments are to be considered and active upon.

Addendum

For the year 2000-2001 only, two Members-at-Large will be elected for a term of one year instead of two years, in order to permit staggering among the four Members-at-Large.

The Canadian Bioethics Society
has its own page on the World Wide Web!
Check out the site at
http://www.bioethics.ca

Canadian Bioethics Society Outstanding Bioethicist – Terms of Reference

The CBS Executive would like to provide the membership with this draft Terms of Reference for the CBS Outstanding Bioethicist Award. Comments and feedback are welcomed. This will also be on the agenda at the AGM in Edmonton.

* *

The Canadian Bioethics Society (CBS) invites nominations for the Outstanding Bioethicist Award. This award may be given every two years and includes lifetime honorary membership to the Canadian Bioethics Society and free registration at the CBS conference in the year of the award.

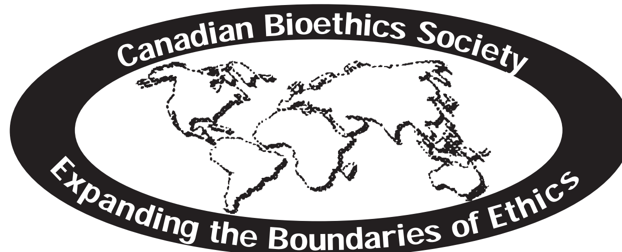
Recipient of the award will be determined by members of the Executive of the CBS and announced in the CBS Newsletter. Presentation will be made at the annual general meeting of the society.

Criteria for selection include:

- Some formal training in ethics or bioethics
- A clear focus on ethics in scholarly and/or clinical work
- National and international profile in ethics
- Active on clinical and/or research ethics committees (past or current)
- Outstanding achievements in research and publication on ethics topics
- Evidence of impact in the field (on students, colleagues, professional publications, advancement of knowledge in the field)

Nominations should be in the form of a letter demonstrating how the nominee matches the stated criteria. Letters of support may also accompany the nomination. Decisions of the Executive will be based on an assessment of how closely the nominee matches the criteria, and will not be subject to appeal. If, in the opinion of the Executive, there are no nominees who fit the criteria, the Executive may decline to make the award in any given year. Only one nominee may be chosen in each award year. A call for nominations will appear in the CBS Newsletter at least two months prior to the Annual Meeting.

Send comments to:
CBS Newsletter Editor
pchidwic@uoguelph.ca



11th Annual Conference
October 28-31, 1999
Westin Hotel, Edmonton, Alberta

KEYNOTE SPEAKERS:

Madeline Dion-Stout • Martin McKneally • John Dossetor • Thérèse Leroux • John Amundsen

Hosting Partners:

- John Dossetor Health Ethics Centre
- Provincial Health Ethics Network
- St. Joseph's College Ethics Centre

… and others

IAB members panel

"Culture, Health and Ethics: Are we ready for the 21st century?"

For more information call (780) 492-6676
www.ualberta.ca/~cbs1999

11th Annual Canadian Bioethics Society Conference
28-31 October 1999
Westin Hotel – Edmonton, Alberta

Thursday 28 October 1999

Pre-Conference

8:00 - 9:00 a.m. **Registration**

9:00 a.m. - Noon: **Health Ethics, Poverty and World Economics**

Noon: **Lunch**

1:00 - 4:00 p.m.: **Cultural Difference and Health Ethics**

This Pre-Conference will explore the boundaries of health ethics in a global context with international leaders in health ethics. Members of the Board of the IAB will address issues relating to the possibility of a global bioethic. The impact that economic position has on ethical issues and the role of cultural values in the conception and practice of health ethics will be explored.

Speakers will be members of the board of the International Association of Bioethics

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Thursday 28 October 1999
11th Annual Canadian Bioethics Society Conference

3:00 - 6:00 p.m. **Registration**

7:00 – 7:15 p.m. **CBS Conference Opening Ceremony**

7:15 – 9:00 p.m. **Public Lecture**
"Ethics, Culture and Health Care for the 21st Century"
Susan Sherwin, Canada
Alastair Campbell, UK
Godfrey Tangwa, Cameroon

9:15 p.m. **Opening Reception**

Friday 29 October 1999

7:30 - 8:15 a.m. **Registration /Breakfast**

8:30 - 10:00 a.m. **Keynote Speakers**
"The Canadian Bioethics Scene"
Madeleine Dion-Stout, Carleton University
Martin McKneally, University of Toronto

10:00 - 10:30 a.m. **Break**

10:30 - 12:30 p.m. **Concurrent Sessions**

12:30 - 2:00 p.m. **Networking Lunches**

2:00 - 3:30 p.m. **Concurrent Sessions**

3:30 - 4:00 p.m. **Break**

4:00 - 5:00 p.m. **Keynote Speaker**
"Up close and Personal in Bioethics: Temptations of Power and Certainty"
Jon Amundson, Clinical Psychologist, Calgary

5:00 p.m. **Social Event**

Saturday 30 October 1999

7:30 - 8:15 a.m. **Breakfast**

8:15 - 9:15 a.m. **Symposia**

HIV/AIDS Vaccine Research:
Quandaries about Care and Treatment –
Ruth Macklin, Albert Einstein College of Medicine
Dale Guenter, McMaster University

End of life –
Jocelyn Downie,Dalhousie University
Hans Van Delden, Utrecht University

Ethics & Cultural Diversity –
Michael Burgess, University of British Columbia
Lesley Paulette, Midwife, Fort Smith, NWT

9:30 - 10:30 a.m. **Concurrent Sessions**

10:30 - 11:00 a.m. **Break**

11:00 a.m. **Keynote Speaker**
"Where do we go from here?"
Thérèse Leroux, Université de Montréal

12:00 - 2:00 p.m. **CBS Annual General Meeting**

2:00 - 2:30 p.m. **Break**

2:30 - 4:30 p.m. **Concurrent Sessions**

4:30 - 5:00 p.m. **Closing Remarks**
John Dossetor, Professor Emeritus, University of Alberta
Marianne Lamb – CBS President - Elect
CBS Conference 2000

Sunday 31 October 1999

Post Conferences

Ethics, Health Care, and Resources at the End of Life

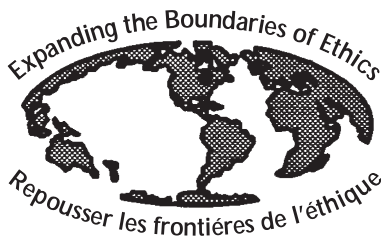
9:00 a.m. - 1:00 p.m.
Steven Lewis, Health Utilization And Research Commission, Province of Saskatchewan
Martin McKneally, University of Toronto
Patricia Rodney, University of Victoria

Hosted by:
John Dossetor Health Ethics Centre
Provincial Health Ethics Network of Alberta
St. Joseph's College Ethics Centre

The Ethics of Health Research Using Qualitative Methods

9:00 a.m. – Noon

Hosted by:
National Council on Ethics in Human Research



Canadian Bioethics Society 11th Annual Conference

October 28-31, 1999
Westin Hotel, Edmonton, Alberta, Canada

REGISTRATION FORM

Note: To receive a confirmation of registration notice, your fax number must be provided.
Please print or type

To register: Complete and return this form by either Fax or Mail to:

1999 CBS Conference Secretariat
11659-72 Avenue
Edmonton, Alberta
T6G 0B9
Fax. (780) 437-5984

For Information about Registration
Tel. (780) 436-0983
E-mail: info@buksa.com

For information about program content and membership
Tel. (780) 492-6676

☐ Dr. ☐ Mr. ☐ Mrs. ☐ Ms. ☐ Prof.

☐ Other (please specify) ____________

Last Name ____________ First Name ____________

Position ____________

Institution ____________

Address ____________

City ____________ Province/State ____________ PC/Zip ____________

Tel. No. (   ) ____________ Fax. No. (   ) ____________

Email ____________

CBS Membership (Sept. 99 – Aug. 2000) Regular ☐ $60 Student ☐ $35
Under or Unemployed ☐ $35 Emeritas ☐ $30

	Before June 30, 1999	**Before Sept 10, 1999**	**After Sept 10, 1999**
Pre-Conference (Oct. 28)			
Regular	☐ $50	☐ $70	☐ $80
Student	☐ $20	☐ $20	☐ $20
CBS 1999 Conference			
Full CBS Member	☐ $225	☐ $245	☐ $265
Full Non-CBS Member	☐ $325	☐ $345	☐ $365
Full Student CBS Member	☐ $90	☐ $100	☐ $110
Full Student Non-CBS Member	☐ $110	☐ $120	☐ $130
Single Day Rate CBS Member			
Friday	☐ $120	☐ $140	☐ $160
Saturday	☐ $120	☐ $140	☐ $160
Single Day Rate Non-CBS Member			
Friday	☐ $170	☐ $180	☐ $190
Saturday	☐ $170	☐ $180	☐ $190
Post Conference (Oct. 31)			
Ethics, Health Care & Resource Allocation	☐ $20	☐ $20	☐ $20
The Ethics of Health Research	☐ $20	☐ $20	☐ $20

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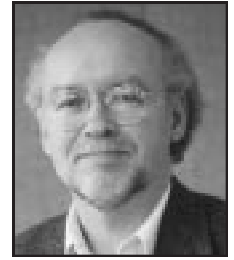
A $60 administration fee will be applied to cancellations made in writing up to and including October 15, 1999. After this date no refunds will be issued. Substitutions, however, will be accepted at any time in writing only.

Pat Murphy

"Only in Manitoba, You Say?"

By Pat Murphy and George Webster



George Webster

As Canadians, we are not accustomed to hearing about court battles over health care decisions. Surely, something remarkably "different" or "unusual" is happening in Manitoba that twice, in as many years, cases involving decisions about "Do Not Resuscitate" orders have been before the Court (i.e. ***Lavallee; Sawatzky***) and engendered much public debate. Stranger still, perhaps, is the fact that neither case involved particularly exotic concerns, but rather, touched on the most basic of issues related to health care decision-making, that is, "How should decisions be made?" and "Who should make them?".

How is it that decisions not to attempt or to discontinue life-sustaining treatment, like CPR, have been a cause of concern in Manitoba and apparently not in the rest of Canada? The answer to this question rests in part with a November 1997 Manitoba Court of Appeal decision in ***Child and Family Services of Central Manitoba v. Lavallee***, 154 D.L.R. (4th) 409 (Man. C.A.). The Court concluded in this case that *"…neither consent nor a court order in lieu is required for a medical doctor to issue a non-resuscitation direction where, in his or her judgement, the patient is in an irreversible vegetative state."*

It is important to briefly review the circumstances of the case considered by the Court of Appeal. According to the factum, a young infant was admitted to hospital following a "savage attack". The young patient was in a confirmed persistent vegetative state. This condition is characterized by severe brain damage with no ascertainable cerebral cortical function. In light of this, care givers and substitute decision makers considered the appropriateness of attempting cardiopulmonary resuscitation (i.e. CPR) in the event of cardiac arrest. The Court was asked to assist with this decision because the young child was under the protection of Manitoba Child and Family Services. Child and Family Services was seeking authorization to have a "No — CPR" order placed on the young patient's health record. The parents of the child did not agree with this decision.

The Court reviewed this case and concluded that a medical doctor, acting on his or her judgement, could unilaterally make the decision that resuscitation not be attempted. While encouraging physicians to take into account the wishes of the patient's family or guardians, the Court stated that *"… neither their consent nor the approval of a court is required."*

On reading this decision, we wrote a piece in our local newspaper, The Winnipeg Free Press (3 January, 1998), expressing our concerns about the conclusion reached by the Manitoba Court of Appeal. There are many challenging aspects of the Court's decision, but, the most troubling was the suggestion that physicians had the "final word" in these matters. In our view, the Court's decision was anachronistic, and in a serious way, wrong-headed.

What are we to make of the suggestion that physicians may write "No-CPR" or "Do Not Resuscitate" orders without the knowledge and/or consent of those most directly affected by this action because these are exclusively **"medical"** decisions?

It is our view that decisions taken in the therapeutic relationship ought not to be simply characterized as "medical" decisions. These decisions terminate in persons, not disease states, and, for this reason, they are, by definition, **ethical** decisions. The judgements we come to in these circumstances communicate value preferences and some conception of the "good" one is seeking or harms to be avoided. These choices are moral choices, not simply judgments of "fact". The idea that medical judgements are primarily decisions about "facts" camouflages or masks the normative considerations embedded in such decisions.

While it is true that physicians bring a particular knowledge, wisdom and clinical experience to these proceedings, we would argue that this knowledge is incomplete without another kind of knowledge; knowledge that only patients themselves, or those who represent them when they can not speak for themselves, can contribute. This knowledge relates to patients' biographies, that is, their values, beliefs and ideas about what is important to them in particular "times, places and circumstances." It is this information that will shape the goals of treatment.

This blending of knowledge of *means* of treatment and *goals* of treatment aptly describes the reciprocal nature of the relationship between physicians and patients. This

reciprocity is ultimately about respect for persons. “Respect” for those involved in these difficult decisions must include an open and honest exchange of views. This conversation ought to occur over time and include communication about diagnosis, available treatment options and prognosis with, and without, interventions. In the specific context of resuscitation, it would be reasonable to explore what the patient and/or family actually understands about this series of interventions.

It is precisely here, though, that there seems to be considerable variation in clinical practice. Many physicians routinely and clearly discuss the matter of resuscitation with their patients. It is also the case, however, that some doctors do not explicitly address this issue with their patients, possibly, because it is a challenging and difficult conversation to initiate. In some instances, the conversation takes place without the patient’s input and the clinical team’s decision is simply announced to the patient as a “medical” decision. In yet other instances, the decision is made without the patient’s input and neither the patient, nor the patient’s family, are informed. Although one would not want to rely exclusively on the public media accounts of what transpired between Mrs. Sawatzky and clinicians at the Riverview Health Centre in Winnipeg for an understanding of this case, one thread that does seem to weave itself through these stories is the fragility of the relationship between the Sawatzky’s and their care givers.

Why such a variation in practice? There are likely many reasons. The one that most often seems to surface, however, in decisions about CPR, is what many now refer to as the “F”-word… “futility”. Some physicians hold that in the face of an expectable, predictable death, attempting CPR is a “futile” effort. In light of this, physicians may not feel any obligation to seek the patient’s agreement, or even to tell the patient that such a determination has been made because the intervention, in their view, is of no benefit.

The so-called “futility problem” is a complex and difficult issue[1] that has, in many ways, been an important hinge in the debate about who makes the decision about whether or not CPR will be attempted and how the decision is reached. As clinical ethicists, it has been our experience that introducing “futility” arguments into this debate is rarely helpful for at least two reasons.

First of all, the concept itself is wanting. This point was deftly made in a Canadian Medical Association Journal editorial written by Dr. Charles Weijer (*CMAJ*, February 24, 1998). Dr. Weijer suggests that the concept of futility is untenable because it …“bundles uncontroversial cases involving treatment that cannot work with cases involving effective treatment that supports controversial ends…” In other words, “futility” mixes together two very different clinical situations. Situations where the treatment cannot do the job it was intended to do, and situations where the treatment can do the job it was intended to do, but people have different and conflicting ideas about the value of the treatment’s outcome.

Secondly, we have also found that the use of futility arguments in the clinical setting tends to erect barriers between physicians, patients and families. Introducing the notion of futility at critical moments in patient’s lives may only serve to curtail important and necessary conversation.

What to make of all this? Ought certain voices in discussions about whether or not CPR is to be attempted be privileged? It is our view that decision making about CPR cannot be respectful of patients, families or practitioners if any party to the decision is either denied meaningful conversation or excluded entirely. Frank and open discussion which explicitly *recognizes* and *identifies* the values of professionals and the personal value commitments of patients or their families is essential.

In “real time”, this discussion is demanding and, more often than not, emotionally exhausting. However, as difficult as these conversations may be, they are invaluable opportunities for all involved in decision making to contribute their very best to the decision making process. No one party to discussions about CPR should simply “trump” the other either by demanding that treatment be provided simply because it has been requested or by silently passing over discussion about these matters and surreptitiously writing a “No – CPR” order in the health record.

In delivering her judgement in **Sawatzky v. *Riverview Health Centre*** (Court of Queen’s Bench of Manitoba, December 21, 1998), Justice Beard observed that the “wider public importance of the ***Lavallee*** case is demonstrated by the fact that others have used that decision as the basis for dramatic changes in the way that they deal with their clients/patients” (p.19). These words seem to go to the very heart of the matter.

When, or if, we frame decisions to attempt resuscitation or not to attempt resuscitation as “one view wins, while the other view loses,” we all lose — physicians, health care facilities, patients and families alike. We will only succeed in further eroding fundamental relationships of trust, relationships between those who are skilled in providing health care and those who seek this human good.

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1. In our view, one of the best philosophical analysis of the “futility” issue is the work Dr. Susan B. Rubin, Ph.D. in: Rubin, S.B. (1998). *When Doctors Say No: The Battleground of Medical Futility*. Indianapolis: Indiana University Press. Also see: Weijer, C. (1999). Why I am not a futilitarian. *Canadian Medical Association Journal. 160* (6), 869-70, for a review of Rubin’s text.

Commentary: The Case of Tyrell Dueck

By Harry Emson

Tyrell Dueck is a 13 year old boy living in Saskatoon. In November 1998 after slight trauma he found a lump on his knee. Biopsy showed this to be an osteogenic sarcoma, and the Cancer Clinic physicians recommended a standard regime of chemotherapy, followed by amputation. The family was unwilling for this and the Clinic physicians applied for, and obtained, transfer of responsibility for Tyrell's treatment to the Department of Social Services. With its consent and the family's acquiescence, two courses of chemotherapy were given. However, early in 1999 when further chemotherapy was due, the family and Tyrell refused consent. They indicated that they wished to seek alternative therapy, consisting of nutrition, herbs, vitamins and prayer, at a clinic in Mexico.

The questions of Tyrell's information, understanding and competence to consent were raised. The family were said to be of fundamentalist Christian belief and with a father dominant, somewhat authoritarian structure. It was suggested that Tyrell was so influenced by his father as to be unable to make independent decisions. An assessment by a psychologist was ordered by a judge, on an application by Social Services. After receiving this the judge formed the opinion that Tyrell was intellectually capable (which I presume means at least potentially competent) but he was not a "mature minor". He was misinformed because of his parents' influence. The remainder of her judgement appears to contradict this, as she ordered that Tyrell remain under the care of Social Services, who could consent to continuance of Cancer Clinic therapy, to which his parents were forbidden to accompany him. It appears to me that it would have been more logical to require that Tyrell be fully informed by whatever means were required, and thereafter permitted to exercise his judicially established potential competence, but this was not her decision. Appeal was contemplated. Before treatment could be restarted, it was found that pulmonary metastases were present and no further conventional therapy was offered. Tyrell's parents then took him to the Mexican clinic, where he underwent treatment.

These are the facts that have been reported in the local and national press, however, there are some others which have not been widely known. The Saskatoon Health District has an Ethics Committee. It has never been consulted formally by the Cancer Clinic; its chairman spoke at one informal staff meeting early in March. The patient and his family were not present, to which he registered his objection. Also in March the Dueck family approached the Committee, but some of the questions it posed for its consideration were considered judgemental, and the Committee refused to answer them. Ethicists outside Saskatchewan and unconnected with the case have given their opinions publicly. The Dueck family has been represented throughout by a lawyer, but Tyrell has not had a lawyer of his own, as might have been the case in Ontario (Globe and Mail 28 Mar 99, A15) where anonymity might also have been enforced. In British Columbia, the determination of Tyrell's competence would have been reserved; under the Infants Act, this would have been presumed unless rebutted. Such is the tangle of law in a Federal state.

Now to commentary and opinion, purely my own. It would be hard to find an ethical principle which has not been violated in the conduct of this case. Its atmosphere has been adversarial and confrontational from the start, its conduct coldly legalistic. As I have said, the judicial decision appears to contain an internal contradiction. There is a reasonable body of bioethical expertise in Saskatoon, which was invoked minimally and at the last minute. The care of the young patient has been expressed only as a statistical chance of survival. And what did the final judicial decision mean? Did it seriously imply that if Tyrell continued to refuse treatment, he should physically be restrained while chemotherapy was administered? Following this, was he to be given an anaesthetic under physical restraint, to awake minue his amputated leg? Our country forbids as unethical some procedures which some people desire to do to children, such as female genetial mutilation; would its legal system physically enforce amputation against the refusal of a 13 year old, of determined competence? Could doctors be found to do this? The situation is reminiscent of the concentration camp experiments, and the only term I can find for it is barbarity. Did the judge envisage this as the logical, possible, likely outcome of her decision?

Saskatchewan has now seen street demonstrations largely focussed on the issues of "alternative therapy" and family right to determine childrens' treatment, linked with fundamentalist Christian belief. It is very easy to judge in retrospect, the only procedure in health care with 100% accuracy. The fundamental questions remain. How do we balance ethics and law? How can we, should we, determine competence on the sliding scale? What are the rights of the child, the family and the community when the family refused conventional therapy, and desires non-conventional therapy not scientifically proven, often on a basis of religious belief? How do we balance these rights, and decide between them? Do we have any pattern by which these cases might be handled to avoid or minimise legalism, confrontation and the adversarial stance? What should have been the process in the Dueck case — could the procedures, and the outcome, been bettered?

Saskatchewan has a knack of generating thorny cases where ethics and law interlace; Halushka, Latimer and now Dueck, where there is material for a conference by every Ethics Committee in Canada

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We're alright Jack

By Charles Weijer

The unexamined life, philosophers tell us, is not worth living. So too, perhaps, the unexamined organization is not worth belonging to. The Canadian Bioethics Society (CBS) is at a juncture requiring reflection, debate, and agreement by its membership as to the very nature of the Society. What is the CBS? Who is it for? What does it do for its members? Should it take stands on issues? All or only a select few?

Perhaps no issue highlights these challenges so clearly as conflicts between the bioethicist and her employer. Imagine the following scenarios:

- During negotiations for an employment contract with a hospital, a bioethicist is told that all contact with the media must be approved by the hospital's director of public relations.
- A bioethicist is instructed by her immediate superior that she must cross the picket line to help administrators run the hospital during a strike by health care workers.
- A bioethicist is dismissed from employment for consulting with a colleague outside the institution about a difficult case.

Two recent documents address the obligations of the bioethicist working as a health care ethics consultant. Francoise Baylis' book *The Health Care Ethics Consultant* (Totawa, NJ: Humana Press, 1994) focuses on the profession of ethics consultation; building on Baylis' work, the American Society for Bioethics and Humanities report *Core Competencies for Health Care Ethics Consultation* (Glenview, IL: ASBH, 1998) examines the practice of ethics consultation. Both documents agree that there are requisite character traits, knowledge, and abilities for the consultant. The above scenarios illustrate the point, however, that the bioethicist's working conditions can impact dramatically on her ability to fulfill her professional obligations as an effective consultant and not merely a compliant employee. For example, the ASBH report states:

> Courage is sometimes needed to enable various parties, especially the politically less powerful, to communicate effectively and be heard by other parties. It is also sometimes required to take positions that are unpopular or contrary to the interests of one's employer or other powerful interests.

A bioethicist working under the constraint of a contractual gag order is effectively prevented from fulfilling this duty.

A clear articulation of appropriate working conditions for bioethicists in Canada would be a valuable guide for both the bioethicist and her employer when drafting conditions for employment. It could be appealed to in the event of conflict in the workplace or in cases of *prima facie* wrongful dismissal — both illustrated above. The need to define adequate working conditions is most acute for those in our profession just entering the workplace. Without a statement of working conditions as a map, the inexperienced negotiator runs the risk of becoming, as Benjamin Freedman memorably put it, a Dagwood to the institution's Mr. Dithers. As the only national organization for Canadian bioethicists, the CBS is a natural locus the development of such a policy. The expertise to develop a statement on working conditions is clearly found within the Society's membership; the majority of bioethicists working as health care ethics consultants are members of the Society; and, a policy with the imprimatur of the CBS will carry more weight than one developed outside of the Society.

The development of a policy on working conditions for bioethicists by the CBS would, however, be a departure from the Society's practice of not taking a stand on particular issues. This practice is not written in stone – it is not, for example, entrenched in the CBS Constitution – and is, therefore, open to question and change. Certainly the CBS ought not take a stance on controverted issues like abortion and euthanasia. The Society should (perhaps) not even involve itself in particular employment disputes. A general policy on working conditions for bioethicists is so basic to the very activity that unites us as a Society,

… continued on pg. 12

We're alright Jack – continued from pg. 11 …

however, that it seems remiss to not engage the problem directly. Legitimate objections can nonetheless be raised to this course of action. Some may object that this step takes the Society in the direction of professionalization — an undesired end to them. Conversely, others, perhaps those most directly affected by a policy on working conditions, may complain that the CBS is not solely a group of professionals engaged in health care ethics consultation and may, therefore, fail to address the issue effectively or authoritatively.

Undoubtedly, readers will be divided as to the merits of the CBS developing a policy on working conditions for bioethicist. Whatever ones position, however, the response "We're alright Jack" is never acceptable when an organization faces such fundamental questions. An effective society responds to the needs of its members. In this case, it is clear that members of the CBS will have to voice their desire for the development of a policy on working conditions for the bioethicist.

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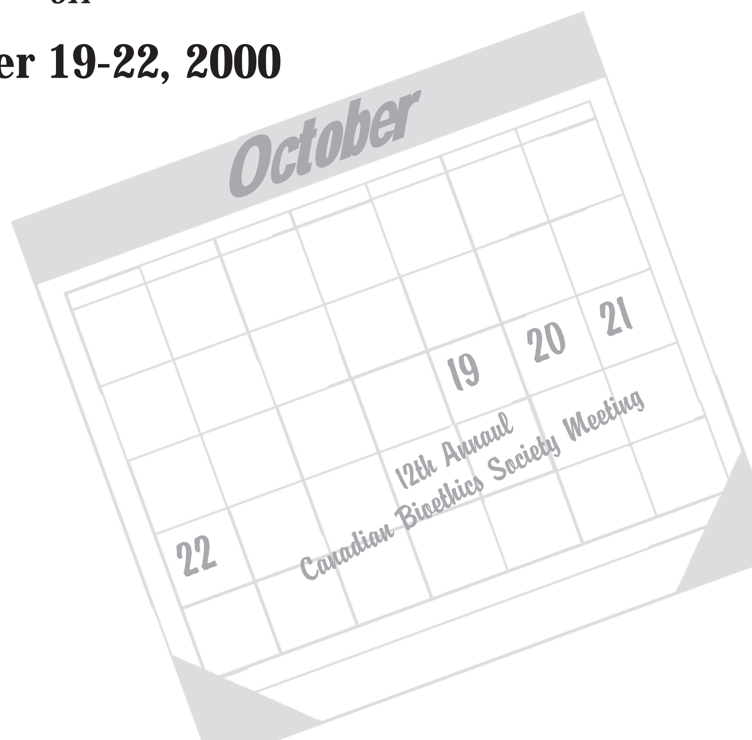

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Please mark on your calendar

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Student Report

By Chris MacDonald

As many of you will recall, last year's Annual Meeting in Toronto featured a Plenary Session, run by students, on the topic "Are Canadian bioethics students being prepared to 'do bioethics'?" That session was so well-attended and well-received that several people suggested that a student-run session become an annual event. The Organizing Committee for this year's annual meeting, in consultation with the CBS Executive, decided not to designate one Plenary Session as a "student" session. The consensus on the Executive Committee, in particular, was that last year's Student Plenary owed its success to the fact that it dealt with a topic + education + into which students have particular insight. In the absence of such a topic, a student Plenary seems undermotivated. Of course, both the Executive Committee and the Organizing Committee continue to see student participation as vital. The number of students who presented at last year's Meeting was truly remarkable, and we all hope this pattern will continue.

Another item of interest to students concerns recent modifications to the Society's Constitution. The Constitution, prior to the current round of modifications, required that the Executive Committee include one student, but did not specify a Student Representative as such. So when I was elected "Student Member-at-Large" at last year's meeting, this was an 'extra-constitutional' move (allowed, but not required, by the Constitution), in recognition of the importance of students within the Society (this was also the case when Laurie Hardingham served in this position before me). The new revisions entrench the position of Student Member-at-Large in the CBS Constitution. This year will be a transition year between the old and the new versions of the Constitution. On the slate of Candidates being presented by the Nominating Committee in this Newsletter, I have been nominated as a "Member-at-Large," and not as a "Student Member-at-Large." I will, of course, continue to represent the needs and concerns of students, and students should not hesitate to contact me (chrismac@ethics.ubc.ca). Beginning in the year 2000, under the revised Constitution, we will have an elected Student-at-Large on the Executive.

By the time this Newsletter goes to press, the deadline for submitting abstracts for this year's Annual Meeting in Edmonton will have passed, so I won't waste space encouraging you students to submit your work. If last year's Annual Meeting was any indication, I know I can look forward to seeing you in Edmonton.

Chris MacDonald recently completed his Ph.D. in philosophy at UBC. He is currently a Graduate Research Associate at UBC's Centre for Applied Ethics, and is the CBS Student Member-at-Large.

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CBS Conference Report from Student Coordinator

By Dianne Godkin

The venue is booked, the keynote speakers are confirmed, the brochures are printed … all that is missing is you! Edmonton awaits your arrival at the 11th Annual Canadian Bioethics Society (CBS) Conference from October 28 to 31, 1999.

As in previous years, a Student Abstract Competition is being sponsored by CBS. The deadline for submissions was June 14, 1999. A conference package including information about the competition, an abstract form, and registration materials was mailed to all CBS members. This information and downloadable abstract forms are available on the CBS web site or on the conference web site located at www.ualberta.ca/~cbs1999.

An additional package concerning alternative student accommodation, as well as possibilities for a student social event was recently mailed to all CBS student members. If you didn't receive this information, please contact me through any of the following methods.

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Hope to see you all in Edmonton!

Candidates for 1999-2000

President-Elect:

Francoise Baylis

Françoise Baylis received her PhD in Philosophy with a specialization in Biomedical Ethics in 1989 from the University of Western Ontario. She is currently Associate Professor of Medicine and Philosophy in the Office of Bioethics Education and Research at Dalhousie University. Prior to this, she worked at the Westminster Institute for Ethics and Human Values in London Ontario, the Hospital for Sick Children in Toronto, and the University of Tennessee in Knoxville.

Dr. Baylis has had a long association with the Canadian Bioethics Society. From 1989-91 she was Secretary-Treasurer, and in 1991, 1992 and 1997 she was a member of the conference planning committee. She is an active member of the society and typically presents her research at the annual meetings. As well, at the last two CBS pre-conference meetings she was invited to give a plenary address.

Dr. Baylis is currently an Executive member of the National Council on Ethics in Human Research (NCEHR) and a member of the Biomedical Ethics Committee of the Royal College of Physicians and Surgeons of Canada. Her areas of research interest include the ethics of assisted reproductive technologies, human cloning, stem cell research, research involving humans, genetics, women's health and paediatrics. She has published and lectured extensively on these topics.

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 Coordinator of Bioethics, Cultural and Spiritual Issues in the Faculty of Medicine and Dentistry, and Professor of Obstetrics and Gynaecology at the University of Western Ontario. His current national positions include co-chair of Health Canada's Advisory Committee on Reproductive and Genetic Technologies, chair of the Ethics Committee of the Society of Obstetricians and Gynaecologists of Canada, Executive of the Canadian Bioethics Society, and member of the National Council on Ethics in Human Research. Jeff received his undergraduate and medical education at the University of Toronto, his residency at U.W.O., and post-doctoral training at U.W.O., University of California, and McMaster University. Jeff's other national and international contributions include the Health Canada Advisory Committee on Embryo Research and national director of the Society of Obstetricians and Gynaecologists of Canada (SOGC). Jeff has written multiple articles and book chapters on scientific and ethical issues and has also written six plays covering issues from woman abuse to HIV to genetic essentialism, as well as many short stories and poems to encourage compassionate health care. 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*

Kathy Oberle is an Associate Professor, Faculty of Nursing, and Adjunct Associate Professor, Faculty of Medicine (Office of Medical Bioethics) at the University of Calgary. She is a member of two research ethics boards at the University of Calgary, and has functioned as ethics consultant to the Alberta Children's Hospital for the past

four years. Teaching responsibilities include a multi-disciplinary graduate level research ethics course (with colleagues from law and medicine) and ethics topics in graduate and undergraduate nursing programs. Her research focus is in the area of clinical ethical decision making, and she has conducted several studies involving clinical nursing and research ethics. She has made numerous presentations at the local, national and international levels on nursing ethics and ethical decision making. As a member of the Canadian Bioethics Society for eight years, Kathy has held positions as member of the Advisory Board, and (currently) as member-at-large.

Student Rep:

No Student representative for this year

Communications Officer:

Paula Chidwick

Paula is an Assistant Professor at the University of Toronto. She graduated from the University of Guelph with a PhD in Philosophy specializing in Bioethics. She obtained clinical experience through an internship at the Sunnybrook Health Science Centre in Toronto. Paula has served on ethics committees at Sunnybrook Health Science Centre and the McMaster Health Science Centre in Hamilton. More recently she sits on the Hospital Ethics Committee at the Guelph General Hospital in Guelph. Paula has worked as a bioethics consultant in Canada and in New Zealand offering bioethics seminars, workshops and consultations to health care professionals. She has taught at several universities over the past 10 years including Wilfrid Laurier University and the University of Guelph. Paula has been a past Executive Committee Member of the Canadian Bioethics Society serving as a Student Representative. Currently she serves as the Communications Officer who is responsible for the publication of the CBS Newsletter.

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.

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