

Canadian Bioethics Society

NEWSLETTER

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CONFERENCE DETAILS

Volume 6, Number 2

August 2001



PRESIDENT'S LETTER

Christine Harrison 2001-2002

In my last President's letter I asked for CBS members to contact me with their views about the Society and what it/we should be doing. I heard from one person, leading me to believe that either everyone is perfectly happy with the way things are going, or everyone is too busy to think about it right now. (I am not even considering the possibility of apathy, as no one I know in the bioethics world is apathetic about anything). I suspect the "busy" answer is the right one.

The offer is still open, especially as the president's term is now two years. Members of the Executive and I would also like to hear from you about issues that have arisen during and between the teleconferences we have had so far this year. Some of these issues may come up at the annual meeting this Fall; here is my 'take' on them – I look forward to hearing yours.

1. Working Conditions. Much of this issue of the newsletter reports on the progress of the Working Group on Employment Conditions for Bioethics. Again, there has been virtually no feedback from the membership on the draft document

which is posted on the website. Michael Coughlin and I presented the document at the Bioethics Seminar of the University of Toronto Joint Centre for Bioethics, and had a lively discussion with members around several points, notably:

- Does the draft document give the impression that those working in bioethics are or should be more ethical than others?
 - Do those working in bioethics share an understanding with their employers about what their role is and ought to be?
- 2. Should the Canadian Bioethics Society identify 'experts' in certain specialty areas of bioethics in response to requests from the media or other groups?**

Occasionally a member of the Executive is approached with this request, and there is some discomfort with giving what might appear to be either a recommendation about someone's credentials or abilities by passing on their name. It might also appear that the person suggested was actually speaking on behalf of the Society. On the other

hand, members of the Executive represent the various regions, and usually know who 'specializes' or is working in a particular area, and could easily pass on that person's name.

3. Questions related to the annual meeting.

Each year many of the same questions arise for the local planning

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Canadian Bioethics Society NEWSLETTER

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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 page 1 ...

committee as have arisen for committees in the past. I hope, before my term is completed, to put together a binder of information that can be updated annually and passed on each year to the next planning group. Some issues are new, however, or require reinterpretation. For example,

- Several years ago Charles Weijer put together an excellent policy regarding commercial sponsorship of the annual meeting. It was recognized that this was becoming more and more of a necessity, and that guidelines and judgement would be required in order to preserve the integrity of the Society. One point in the guidelines states that "[t]he organizers of the Annual Meeting may seek or accept funding from commercial sponsors provided that such funding is (i) in accord with these guidelines and (ii) approved by the CBS Executive Committee." The Executive would like to hear from you, the membership, what your thoughts are as to how we should make these decisions.
 - What should happen to the profits generated by the annual meeting (should there be any)? We have struggled with this one. It has always been understood that our annual meeting is a great benefit and opportunity for our members, and that those organizing the conferences have done so as a service to the Society. Hosting one of these conferences is very hard work – planning, grant applications, program development, abstract review, etc., etc., etc. It was not seen to be fair to place the financial risk and responsibility on the organizing committee – this has been assumed by the Society with the understanding that the Society would also receive any profits. These would be dedicated to Society business and projects, including providing a 'cushion' in case future conferences were operated at a loss. We are now reconsidering this practice, including the possibility that some portion of the profits might be returned to the organizing group for a bioethics related activity, with the rest perhaps providing a small fund to which members might apply for funding small projects. Details are being worked out by Marianne Lamb and Kathy Oberle – please send me any suggestions you have and I will see that they are passed on.
 - How much autonomy does/should the organizing committee have?
- 4. Other questions we have discussed, and which I am sure will arise again, include**
- How feasible would it be, given the size of our Society (and corresponding financial situation) to have a National Bioethics Week?
 - Do we still need to alternate the presidency of the Society between a health care provider and non-health care provider?
 - Should the Society ever "take stands" on issues?

My email address is christine.harrison@sickkids.ca. I look forward to hearing from you.



Bioethics at the Beginning
of the 21st Century

**13TH ANNUAL CONFERENCE AND MEETING OF
THE CANADIAN BIOETHICS SOCIETY**

October 11-14, 2001

The Fairmont Winnipeg • Winnipeg, Manitoba

Members and friends of the CBS are invited to meet “at the heart of the continent” for the 13th Annual Meeting and Conference of the Canadian Bioethics Society as Winnipeg hosts:

“Imagine...Bioethics at the Beginning of the 21st Century”

The Fairmont Winnipeg

October 11-14, 2001

This year's **Pre-Conference Day** (Thursday, October 11) will focus on “*Ethics Consultation: Some Basics and Beyond*” opening with Christine Harrison's (Hospital for Sick Children, Toronto) reflection “Ethics Consultation: The State of the Art” and closing with “Ethics Consultation: A Cautionary Tale” given by George C. Webster (St. Boniface General Hospital, Winnipeg). Four concurrent workshop's addressing “Models and Approaches”; “Knowledge Skills and Abilities”; “Ethical Challenges”; and “Evaluating Ethics Consultation” will complement the program.

The **Conference** (Thursday, October 11 – Saturday, October 13) will blend five plenary sessions with concurrent papers and workshops as well as a poster event and book display. The invited plenary speakers include: Rex Murphy (CBC, Toronto); Susan Rubin (The Ethics Practice, Berkeley, California); Arthur Frank (University of Calgary); Carl Elliott (University of Minnesota, Minneapolis) and Francoise Baylis (Dalhousie University, Halifax).

During the Conference, the CBS will proudly present the premiere of “Sarah's Daughters”, a new play by Jeff Nisker dealing with ethical issues in genetic testing.

The **Post-Conference Morning** (Sunday, October 14) will spotlight “Ethics and the Media” opening with “Bioethics and the Media: A Sketch of the Moral Landscape” provided by Vince Carlin (Ryerson School of Journalism, Toronto) and a panel “Sound Bites...Sound Ethics?” Featuring Margaret Munro (The National Post); Charles Weijer (Dalhousie University, Halifax) and Arthur Schafer (University of Manitoba, Winnipeg).

*For program and registration information please consult the CBS 2001 Conference Website:
www.hsc.mb.ca/cbs2001 or call the CBS 2001 Office at 204-235-3619.*

WORKING

A Report from the Ad Hoc Working Group on Employment Standards for Bioethics

Michael Coughlin (Chair), Eoin Connolly, Christine Harrison, Marie Hirtle, Abbyann Lynch, Chris MacDonald, Pat Murphy, Paddy Rodney, Mary Rowell, and George Webster

What should happen when an ethics consultant working within an organization is in significant ethical disagreement with authorities in the organization, perhaps with the employer, and is faced with either taking the risk of confrontation with the employer or acceding to moral compromise? This is an issue that the Society has been exploring since a resolution made at the 1999 annual meeting. A draft discussion paper on "Working Conditions for Bioethics in Canada" was presented to the members at the last annual meeting and published in the February 2001 CBS Newsletter.

The potential for conflict is summarized in the "Core Competencies for Health Care Ethics Consultation" (American Society for Bioethics and Humanities, 1998):

"Giving advice or otherwise acting against the institution's perceived financial, public relations, or other interest may pose potential harm to ethics consultants' personal interests. This issue should be addressed proactively with the health care institution by any individual or group that plans to offer ethics consultation in that institution."

The goal of the CBS task group on working conditions is to address such issues in order to create a model by which organizations might deal with the conflict "proactively." It outlines ways by which the parties involved might avoid such conflicts, or, if necessary, resolve them. In addition, the Society believes that it should support the moral integrity of members who might be involved in such conflict and will examine ways by which that might be accomplished. Our previous report argued that the "special role of the ethicist – including in particular the role of commenting on the ethical conduct of the organisation as a whole" would require some special protections. We now suggest some ways in which that protection might be offered.

In order to protect the integrity of the ethicist, we will need to be able to say something about the internal morality of the profession itself, and this in turn will require some description of the role of the bioethicist. The Working Group believes that, while there is still no canonical job description for bioethics, bioethicists currently constitute a sufficiently coherent occupational group for it to be possible to outline a reasonable set of ethical constraints that are applicable to most or all people who hold the title of "ethicist," "bioethicist," or "health care ethics consultant."

- 1) Our first task then, is to outline what might be considered a model role description of a health care ethics consultant.
- 2) From that we will move on to the beginnings of a code of ethics for ethicists which will set out a set of standards by which a conflict can be evaluated.
- 3) We will then outline a response to conflict that can serve as a means for addressing situations in which the ethicist finds him or herself in ethical conflict with the organisation.
- 4) Finally, we will look at some future possibilities for the development of the professional aspect of ethics consultation. This could include the possibility of some sort of credentialing process. Other possibilities may arise out of ongoing conversations with the American Society for Bioethics and Humanities (ASBH), and out of focussed conversations within the CBS.

1) Role Description of the Bioethicist

The bioethicist is encouraged and expected to provide advice and critical analysis to persons at all levels of the organization regarding ethical issues and institutional values. He/she can influence how well ethical issues are discussed and addressed in the provision of patient care and the development of organizational policy.

CONDITIONS

The role of bioethicist takes on different forms in different settings, and those who are named bioethicist do not all engage in the same kinds of activities. The job descriptions of bioethicists usually involve responsibilities in the areas of: 1) clinical case consultation; 2) education for staff and students; 3) research and publication; and 4) organizational functioning (often through policy formulation or participation on various committees). And while not all bioethicists may be active in all these areas, it is ethical issues and values conflicts that arise in any of these areas that become the particular focus of the bioethicist's responsibility.

To some extent within a large organization of persons with different personal and professional backgrounds, conflicts and differences of opinion will arise. Given the sensitive nature of the bioethicist's role, there may be more than the usual occasions where disagreement and conflict occur. Nevertheless, the hospital should recognize the bioethicist's obligations to responsibly raise what may sometimes be controversial issues, and support him/her in these circumstances. Such support might include access to mutually agreed upon peer review, independent legal counsel, mediation, and due process. The Canadian Bioethics Society is also available as a resource and support.

2) Internal Morality of the Profession: A Code of Ethics for Ethicists

What would a code of ethics for ethicists look like? Freedman (1994) argued that "The task of delineating a profession's internal morality relies on a prior specification of purpose." Freedman further argued that, in the absence of a canonical job description, the task of describing the internal morality of health care ethics consultation reduced to describing suitable employment conditions. Clearly the question of working conditions and the question of ethical conduct by bioethicists are deeply interrelated. The Working Group believes that, while there is still no canonical job description for bioethics, bioethicists currently constitute a sufficiently coherent occupational group for it to be possible to outline a reasonable set of ethical constraints that are applicable to most or all people who hold the title of "ethicist," "bioethicist," or "health care ethics consultant."

A code of ethics must have the formal endorsement of the organization, as well as the informal support of as many of its members as is reasonably possible. The beginnings of the Code of Ethics presented here will be developed by the Working Committee through several drafts before bringing it before the Membership for comments, revision, and then finally ratification.

Presented below is the draft outline of how a Code of Ethics for Bioethicists might be formulated. Also presented are some possible statements of specific obligations that bioethicists should adhere to. This is intended to serve as a starting point for discussion. Note that the final version of the Code will not be exhaustive of every obligation that could be attributed to bioethicists. No code ever is exhaustive. The attempt should be to capture the key obligations that must be adhered to in order to maintain the integrity of bioethics as a burgeoning profession. The Working Group believes that the focus of this Code should be upon ethical considerations that are of special relevance to the role of bioethicists, and to issues that have caused particular concern in the past.

Outline for a Code of Ethics:

1. Preamble:
 - a) What is a Bioethicist?
 - b) To Whom does this Code Apply?
 - c) Do Bioethicists Have Special Ethical Obligations?
 - d) Bioethics and the Ideal of Professionalism
2. Obligations to Whom?
[this is intended as an ordered list]
 - a) To Patients and their Families
 - b) To The Public
 - c) To The "Profession"
 - d) To Students
 - e) To Co-workers
 - f) To Employer Institutions

Specific Obligations:

- I will conduct myself in a professional manner, and strive for exemplary levels of honesty and integrity.
- I will foster an awareness of the limits of my own expertise when conducting clinical consults, drafting or revising policy, educating, or dealing with media.
- To the extent permitted by law, I will hold confidential information divulged to me by patients, patients' families, administrators, or members of health care teams.
- I will strive to avoid conflict of interest (i.e., situations in which either a personal interest conflicts with my official duties, or in which the goals of one of my institutional roles conflict with the goals of another of my institutional role). When such conflicts arise, I will take action by first divulging the conflict to the interested parties and then, if necessary, by removing myself from the decision-making process.
- I will advocate for conditions of employment that will permit me to conduct myself according to the ethical standards outlined here.
- I will avoid abusing the power that my institutional role and special training give me.
- I will never abuse my position of power in order to exploit those I serve.
- I will contribute, where possible, to the advancement of the field of bioethics, whether through peer-reviewed publication, teaching, mentoring, or public education.
- I will avoid any action or statement that is likely to bring the field of bioethics into disrepute.
- Whenever my institutional position permits, I will strive to ensure that other ethics consultants are subject to working conditions that are conducive to the effective and ethical pursuit of the goals of our profession.
- I will strive for continuous learning, and to remain current regarding advances in bioethics, law, and health care sciences to the extent required for excellent work in my field.

3) Attending to Professional Conflicts

Occasionally situations may arise in which “(g)iving advice or otherwise acting against the institution’s perceived financial, public relations, or other interest may pose potential harm to ethics consultants’ personal interests” (ASBH, Core Competencies). Such a situation is often framed as a conflict between the professional autonomy/integrity of the ethics consultant and the obligation of loyalty to the organisation. This conflict is played out in society in many different ways and is certainly not limited to being a dilemma for professionals. In the area of health care, it has been most discussed around questions of whistleblowing in biomedical research and was one of the major topics of Presidents’ Commission for the Study of Ethical problems in Medicine and Biomedical and Behavioral Research (Whistleblowing in Biomedical Research, 1981).

The “Joint Statement on Preventing and Resolving Ethical Conflicts” begins to address issues of disagreements among health care providers and between health care providers and administration (Part I.14). It also addresses issues of professional autonomy (Part I.16) and calls for the establishment of a well defined process for dealing with ethical conflict. While the Joint Statement is concerned primarily with disagreements regarding health care decisions, the general thrust of the guidelines could well be applied to other kinds of disagreement. What it does call for is a defined, open process that respects the judgment of all involved. How institutions might establish such processes will need to be examined at a later stage.

For its part, the Working Group believes that the CBS should formalize some sort of support process whereby there would be named a small group who would be able to offer peer support for members facing serious conflict with an employer. What would follow after that is something that needs to be further examined. Should there be some kind of a fact-finding mechanism? Would peer support be sufficient? What about confidentiality issues? All of these things would have to be looked at. We could have a two-step process – first, we would set up and publicize through the CBS a group of people knowledgeable about the issues who could provide support for members who found themselves in a serious conflict situation. How this would be put into play would need to be discussed at the executive of the CBS. Step two would be to present this idea to the CBS at an annual meeting and look for consensus on such an approach.

4) Future Directions

A. The ASBH Clinical Ethics Task Force:

The Clinical Ethics Task Force was established by the American Society for Bioethics and Humanities (ASBH) early this year. This Task Force is chaired by Susan Rubin and is intended to continue some of the work undertaken by the ASBH committee that prepared the publication *Core Competencies for Health Care Ethics Consultation*. Membership on the Clinical Ethics Task Force includes a wide range of disciplines, perspectives and in Sue Rubin's words, "generations" working in the field of bioethics. Two Canadians, Francoise Baylis from Dalhousie University, and George C. Webster from St. Boniface General Hospital were invited to participate in the work of the Task Force.

The ASBH Task Force group has had one teleconference call and different tasks have been assigned to small working groups. The members of the Task Force will be looking at the following questions:

1. What is the actual state of clinical ethics as it is being practiced?
2. Who is doing clinical ethics? What is their training?
3. What methods/approaches do clinical ethicists rely on?
4. What is the quality/competence of the work being done?
5. What has been the impact of the Core Competencies document?
6. What are the current unresolved issues in clinical ethics and ought ASBH consider taking a stand on any of them?
7. What are the most effective methods of studying these questions?

The Task Force envisions meeting over the next year and plans to submit substantive recommendations to the ASBH Board and membership. These recommendations may affirm or complement recommendations from the CBS membership and permit further joint effort on these issues.

B. Credentialing

As those doing health care ethics consultation increase, there is an increasing focus on the professionalization of the discipline and discussion of a need for some kind of credentialing (Sherwin, 1994). In addition to the advantages and disadvantages discussed by Sherwin, we recognize that some process of credentialing may also give rise to a mediating structure that could offer some recourse or protection in situations of conflict between a bioethicist and an employer.

Interviews with people working in several of the regulated health professions suggested various ways in which groups become credentialed, and revealed common experiences among them. Issues that came up in discussions were:

1. What term to use? What name do we want? (ethicist, bioethicist, health care ethics consultant, etc.)
2. What kind of knowledge is required?
3. Can we identify a collection of relevant university studies = a faculty
4. Could we devise a "test" for certification.
5. Devise a common national curriculum and national test for certification
6. Could we devise further tests for specialties
7. How would we set level of competence for "foreign trained" individuals
8. What other criteria would we specify (e.g. character issues)?

Several themes emerged in looking at the evolution of the professions we examined. All had difficulties determining precisely what their name would be, and what knowledge would be required for credentialing. Another emerging theme was the importance of a concentration in one place (primarily a university faculty) of people in the field who could develop the discipline. Eventually, these could link with national groups in establishing a regulatory body.

Another approach, which avoids a need for legislation for the group, is to look at certification by means of a written exam and evidence of continuing education.

What directions to take around this issue is a question that needs to be brought to people engaged in the field. It will be one of the topics raised in the focus groups at the annual meeting.

C. Focus Groups

The CBS Ad Hoc Working Group on Employment Standards for Bioethics will host a focus group for interested individuals who are active in ethics consultation and other related ethics work. The focus group will take place during the networking lunch portion of the Annual CBS Conference on Friday, October 12, 2001, and will last for approximately 1.5 hours. We will be running the focus group according to qualitative research methods. This means that it will be an open-ended group discussion facilitated by a convener with assistants there to observe the content and process of the discussion.

The purpose of the focus group will be to gather more information about the experiences of individuals who consult on health care ethics and to obtain some feedback on the progress of the CBS Ad Hoc Working Group to date. The convener will direct the discussion towards these two ends, while facilitating as much open ended exploration as possible.

The focus group will provide the CBS Ad Hoc Working Group on Employment Standards with a unique opportunity to gather data from experts in ethics across

Canada, and so we will audiotape the session and make notes during it. Participation in the focus group

will be voluntary, and confidentiality will be protected. A consent form that details how voluntariness and confidentiality will be protected will be available prior to the Conference (as well as at the Conference).

If you are interested in learning more about the focus group and/or wish to participate, please contact Patricia (Paddy) Rodney RN, MSN, PhD c/o Langara College, 5th Floor, Library Building, 100 West 49th Avenue, Vancouver, BC, Canada, V5Y 2Z6; Office Tel: 604-323-5923; Office Fax: 604-323-5929; E-mail: prodney@direct.ca

CONCLUSION

This is the second report from the "Ad hoc Working Group on Employment Standards for Bioethics." It is part of the attempt to respond to the mandate given by the membership of the CBS to look at the issues of employment and working conditions for ethicists practicing in non-tenured environments. This is a work in progress and the "Working Group" invites members to respond to this second report with suggestions or comments to any of the members of the group. A further version of this report, revised in the light of comments received, will be presented at the Annual Meeting of the CBS in Winnipeg in October of 2001.

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CBS 2002 ANNUAL GENERAL MEETING **Victoria, B.C. • October 17-19th, 2002**

focusing on

"Ethical Challenges Throughout the Lifespan"

CO-CHAIRS: VERONICA MORRIS & JANET STORCH

Watch for details.

REFLECTIONS ON ROBERT AND TRACY LATIMER ETHICAL ISSUES FOR SOCIETY

Elizabeth J. Latimer, MD, CCFP, FCFP

The reader will be familiar with the details of this high profile case. The rightness or wrongness of Robert's actions have been and will continue to be widely debated. It is not my intention to do so here. Rather, I would like to consider other aspects of the situation, those ethical issues that are of great importance to society and to you and I but which are often overlooked. All of us at one time or another will assume the caregiver role for a loved one. Do we know enough about the dynamics of caregiving, about the lives of courage and perhaps of quiet desperation of caregivers? Do we, in our society, our health care and social support system do enough to support caregivers?

Mr. Latimer, at some point, came to believe that his daughter would be better off dead. How might a person reach such a point regarding their loved one? It is crucial that we consider this in order to seek some understanding of Robert's actions and to help others who are in a caregiving role.

UNRELIEVED PAIN, SUFFERING AND DISTRESS

There are two dimensions to pain and suffering, the actual experiences of the sufferer and the perceptions of those who love and care for that person. Physical pain and suffering are very closely entwined and distress of an emotional nature is often perceived as pain and can be very upsetting to all involved. If one's loved one is distressed and frightened it can be very difficult to watch even though health professionals reassure that "the pain is not physical".

We have grossly inadequate services for the relief of pain and suffering in Canada. Acute pain programs, palliative care programs and services that might provide support to distressed caregivers at home, in hospital and longterm care, such as Chaplaincy, psychology and social work, are often viewed as "soft" and are being cut in our increasingly "give us the numbers" mentality in health care and social services.

LACK OF EFFECTIVE CAREGIVER SUPPORTS

Our relationships with our loved ones are not intellectual and cerebral in nature. Rather, they are lived at a complex emotional level even when we are in the best of health. The stresses of caregiving will magnify this further. Fatigue, worry, irritation, sadness, fear and anxiety co-exist with the enormous sense of responsibility to determine what is best and right for a loved one who cannot speak for him/herself. There may be concern for other loved ones who are providing the daily care and the burden which such care is placing upon them. This may be on-going for many years.

"We have grossly inadequate services for the relief of pain and suffering in Canada. Acute pain programs, palliative care programs and services that might provide support to distressed caregivers at home, in hospital and longterm care, such as Chaplaincy, psychology and social work, are often viewed as "soft" and are being cut in our increasingly "give us the numbers" mentality in health care and social services."

I believe that caregiving can be considered to be of four types... high intensity emotionally and physically over a short time, low intensity over a long time, low intensity over a short time, and high intensity over a long time. High intensity caregiving over a long time may be the most difficult to endure. Such, perhaps, was Robert's situation.

Given an intensive stress over a lengthy time, any human being might experience thoughts which are considered unacceptable and unspeakable in our society. "I don't want to do this anymore", "I wish this was over", "She would be better off dead", and, in extreme situations, "I will end his life and mine too". Because such thoughts are viewed as "bad", they engender feelings of guilt and may not be shared. If shared, the response they elicit may be non-supportive..."you mustn't think that way or say those things". One might not share such feelings for fear that society might take one's loved one away. Thus, a desperate thought may be born of fatigue and worry and grow in isolation until it is seen as the only course of action that is possible.

What about home care services and respite care? Can't these help prevent such stresses and strains? Well, ideally these would form options for support of the caregivers in long term caregiving situations. The reality, however, is far from good. Our home care services in Canada are

piecemeal, and fragmented and grossly under-funded when compared with hospitals. Nurses and others may visit the home, but there is no provision of shifts of care which would allow more time away from the caregiving task. The major caretaking responsibility remains with the family. Respite care for adults and children in Canada is virtually non-existent. We haven't made this a priority. Where it does exist it must be planned long in advance, for limited time periods and perhaps only once a year. Hardly a relief from the caregiving role. Also, the move to a respite care setting can cause distress to frail people of reduced intellectual capacity. This is not emotionally comforting to families to do this to their loved one even though they themselves desperately need a break.

SEEKING SOLUTIONS

As a society and as neighbours, relatives and friends, we must fully accept our ethical responsibility to support caregiving families. This will require a real commitment in terms of designating resources (people and money) and developing the necessary systems of care. It also requires recognition and valuing of the role of the caregivers, those people who assume a task out of love and carry it out with great heroism.

What would help them in their task? Let us hear it in their own voice.

- Relieve my loved one's physical pain effectively and in a timely manner.
- Relieve my loved one's emotional and psychological distress and fear.
- Respect my loved one. See her/him as the unique person they are.
- Help me to see the ways that my loved one gives to me and to the family. Help me to see the reciprocity between us¹.
- Listen to me. Take me out on the porch for a cup of coffee and ask me how I'm doing. Give me sincere praise for the caregiving which I provide.

- Reassure me that anyone can get tired of on-going caregiving and that I am not alone or a bad person if I get tired of the job sometimes. Don't force me to "go underground" with my thoughts and feelings by telling me to be brave. Give me permission to share my feelings and thoughts..."Many people in your situation tell us that they sometimes feel they can't go on any longer. Have you ever felt like this?"
- Give me a Team Leader or Case Manager and a caregiving team who know me and my family, and will provide the "four c's and three a's" of care: compassion, competence, communication, companionship, attentiveness, accompaniment, and advocacy².
- Provide me with skilled, compassionate and familiar caregivers who will come into my home for a week-end around the clock so that I and my family can get away sometimes... maybe once every month would be good, but let me tell you how often I need this. Don't force me to wait longer than I can stand.
- Develop respite care settings near my home and make them readily accessible, so I can phone up and book one or two weeks perhaps once per three months. Make these settings attractive, person-centered and expert at their task.
- Provide me with support groups in my neighbourhood. Organize and run them for me. I am too occupied with my care task to take on another job³.
- If you are my neighbours, family or friends, please help me as you are able. Drop over for coffee. Offer to stay with my loved one for an afternoon or evening on a regular basis. Ask me if there are other tasks with which you can assist me and my family. Include us all in your social circle. Invite us to your home.
- Try to imagine what it is like to walk in my shoes.

Dr. Latimer is a consultant physician in Palliative Care and Pain Management at the Hamilton Health Sciences and Professor, Department of Family Medicine, McMaster University, Hamilton, Ontario. Although sharing the surname of Tracy and Robert, she is not related to them.

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BIOETHICS WEEK IN ALBERTA

Erin Cooper

February 12-18, 2001 marked the first province-wide Bioethics Week in Alberta, held in effort to facilitate widespread discussion and education around bioethics issues. The event was coordinated by Alberta's Provincial Health Ethics Network (PHEN) in partnership with the bioethics organizations in the province: the John Dossetor Health Ethics Centre (University of Alberta), St. Joseph's College Ethics Centre, the Redemptorist Bioethics Consultancy, and the Office of Medical Bioethics (University of Calgary).

The initiative also benefited from the support and acknowledgement of municipal and provincial governments. The period was officially proclaimed Bioethics Week by the Alberta Minister of Health and Wellness as well as by the Mayors of Calgary and Edmonton.

The vision for this initiative was that institutions and organizations across the province would host their own health ethics events. Primary goals of the week were to: (1) emphasize the importance of examining values underpinning the health system, (2) facilitate the health ethics education of various stakeholders in the system, and (3) provide greater visibility in the province to bioethics committees. It was hoped that a designated week highlighting the subject would provide a vehicle through which to promote widespread and sustained awareness of the importance and relevance of bioethics to all Albertans.

PHEN's role as coordinating body involved facilitating connection between the various bioethics partner organizations, developing resources and publicity

materials for use by potential event planners, encouraging widespread participation in the event, running a provincial publicity campaign, compiling a listing of the Week's events, and coordinating an evaluation of the project. Some of the resources provided by PHEN included a comprehensive *Bioethics Week Activity Guide* containing a multitude of ideas and guidelines for planning an event, as well as promotional materials (i.e. posters) that could be adapted to publicize local events. PHEN coordinators were also active participants throughout the week, traveling across Alberta to present various workshops and lectures.

Bioethics Week partner organizations were responsible for making a financial contribution towards the cost of producing resource materials, reviewing drafts of these materials, offering speaker suggestions and other information and support to organizations interested in hosting events, as well as holding events of their own during the Week.

At least fifty bioethics educational events were held over the course of the Week, with participation from well over 1000 individuals. The events took a variety of formats, ranging from panel discussions, brown bag lunches and

dramatic presentations held for public audiences, to education and resource development activities geared towards particular ethics committees. Feedback received to date from event participants and coordinators has been largely enthusiastic and supportive of the initiative, acknowledging the importance of explicitly directing time and energy towards these issues and looking forward to even broader participation in future years. Ethics committees



in particular have reported that the Week has provided an important and valuable opportunity to host educational events for their constituents (be these institutions or regional communities) in a supported manner.

Some of the challenges that arose in planning the Bioethics Week project included: finding and choosing a time period that worked well for the majority of stakeholders and was not in conflict with other events; distributing information and resource materials to potential event planners sufficiently in advance to allow time for organization and participation; and facilitating the involvement of community groups outside of the traditional health care system.

The Network staff, along with its Bioethics Week partners, will be meeting over the summer months to plan for next year's Week and determine how best to broaden the scope and reach of the event. Pending further analysis

and evaluation it is anticipated that Bioethics Week will become an annual event in Alberta.

If you would like more information about Bioethics Week, please visit the PHEN website at www.phen.ab.ca or contact the Northern Alberta office at (780) 492-8239. The *Bioethics Week Activity Guide* can be purchased for \$25.

If you would like assistance with implementing a *Bioethics Week* of your own, please feel free to contact PHEN or any of its partner organizations – all of whom are interested in and committed to helping share this experience as widely as possible.

Erin Cooper is a Research and Programming Assistant with the Alberta Provincial Health Ethics Network.
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CHAIR IN MEDICAL ETHICS

The Vanderbilt University School of Medicine invites applications for the Ann Geddes Stahlman Chair in Medical Ethics, to begin July 2002. The Stahlman Chair is a fully-endowed Chair in the School of Medicine and is explicitly designated to contribute to the promotion of humanism in medicine. The individual who holds this Chair may be, by background and training, a scholar in ethics, philosophy, non-denominational theology, law, or medicine. Applications are sought from distinguished individuals with strong records of scholarship, teaching, and experience in the field of medical ethics. The Stahlman Professor is expected to be appointed with tenure at the level of Professor. Send letter of interest, CV, and names with contact information for at least three references, to:

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GREETINGS TO ALL STUDENTS

Marie-Eve Bouthillier

The first item I would like to discuss in this report is the student abstract competition.

Firstly, I would like to acknowledge the excellent work done by Marie Edward, who was responsible for organizing this year's competition. She did a wonderful job and I would like to congratulate her on behalf of all student members. Several abstracts have been submitted for the competition and are presently under review by the judges. The results should be available at the beginning of July.

This year, the CBS is offering eight \$500 bursaries to the winners of the competition. The abstracts are reviewed by judges who are themselves graduate students. The proposed criteria for the review of abstracts are as follows:

- 1) Relevance of topic to the field of bioethics and assessment of timeliness of topic in relation to issues/debates current in the field;
- 2) Ability of abstract to capture your interest – creativity, new or fresh perspective on topic;
- 3) Strength of arguments – clarity, precision, logical rigour, cogency;
- 4) Soundness of research methodology/ theoretical framework/ method of analysis (The idea here is to accommodate a range of approaches, from a biomedical research model to a more theoretical approach.);
- 5) Strength of data/ sources (Is there evidence of an understanding of enduring literature related to the topic? Are arguments/ claims supported by data/ sources provided?).

Each of these criteria is worth 10 points for a total of 50 points.

Marie Edward and Mylène Deschênes, last years' president of the student abstract competition, have suggested that a permanent set of criteria be established in order to simplify the organization of the competition and make the judge's task easier. Also, this would allow students to become familiar with the criteria in advance. Furthermore, it has been suggested that a fixed deadline be established for submissions. This year, the deadline was initially set for April 15, and then later extended to June 1st. I would like to hear your opinions regarding these proposals in order to outline a procedure that could be followed from year to year. Thanks again to Marie Edward for her hard work.

The second item I would like to discuss is the upcoming conference in Winnipeg in October. In my last report, I had invited students to contact me about planning a plenary session on a topic of concern to students. I received a few e-mails, but the idea has now been put aside since students were expected to provide an official plenary session abstract. The organization of a plenary session requires significant time and experience, and it seemed too difficult a task for me to take on this year. However, I will throw out the idea again at the upcoming student network lunch and we can re-discuss the possibility of a student plenary session for 2002.

I am still wondering about the possibility of organizing a social event for students at this year's conference, as there are apparently no bioethics students in Winnipeg at the moment. Several student members sent me their ideas and we have decided that it would be nice for students to get together for a drink in an informal setting. Those students who will be in Winnipeg in October and who are familiar with the city are welcome to suggest a place where we can meet.

My last point concerns the creation of a Web page for students within the CBS Website. I have passed the idea on to Chris MacDonald, the current Webmaster for the site, and he has confirmed that it would be possible to have a separate e-mail address for students. All information pertaining to students would be on this page. However, specific content still has to be determined. I would like to get this page together as soon as possible in order to present it at the upcoming conference. Once again, all of your suggestions are welcome.

Finally, I would like to congratulate all of the students who participated in this year's abstract competition and I invite you all to attend the conference in Winnipeg. This year's theme is *Imagine! ... Bioethics at the dawn of the 21st century.*

Erratum

My apologies to Patrycja Maksalon who was also a winner of the 2000 competition. The title of her abstract was «Challenging Practice Discourse: The Medicalisation of Violence Against Women».

Marie-Eve Bouthillier is a PhD candidate in applied social sciences, specializing in bioethics at the Université de Montréal.

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CANDIDATES FOR 2001-2002

Members-at-Large:

Eastern — *Kathleen Cranley Glass*

Kathleen Cranley Glass is a clinical ethicist and health care lawyer at McGill University's Biomedical Ethics Unit, with academic appointments in the Departments of Pediatrics and Human Genetics. She is also the Clinical Ethicist at The Montreal Children's Hospital. Dr. Glass holds a master's degree in political science from the University of Chicago and LL.B. and B.C.L. degrees from McGill. She received a doctorate in health law and ethics from the Institute of Comparative Law at McGill. Dr. Glass is currently the Director of McGill's Biomedical Ethics Unit in the Faculty of Medicine.

From 1993 to 1994 and again in 1996, Dr. Glass was Acting Director of the National Council on Bioethics and Human Research (now the National Council on Ethics in Human Research), where she is currently a Council member. In 1994-1995, she was a Visiting Fellow at Harvard Medical School's Division of Medical Ethics. Since 1997, she has been the Principal Investigator of McGill's Clinical Trials Research Group, an interdisciplinary research team concerned with ethical and legal issues associated with research involving humans. Her research is funded by the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council.

Dr. Glass teaches ethics in McGill's Faculty of Medicine and Department of Human Genetics. She is a member of the clinical and research ethics committees of The Montreal Children's Hospital, the National Cancer Institute of Canada's Data Safety Committee and the Boards of Directors of the Fonds de la recherche en santé du Québec and the Canadian Pediatric Foundation. She was recently appointed to the Advisory Board of the Institute of Human Development and Child and Youth Health of the Canadian Institutes of Health Research.

Her research interests include ethical and legal issues involving children, the elderly, psychiatric patients and research subjects as well as the design, review and implementation of clinical trials, in particular, genetics trials.

Atlantic — *Dr. Carolyn Ells*

Dr. Carolyn Ells, R.R.T., Ph.D., is an Assistant Professor in the Department of Bioethics, Dalhousie University. Dr. Ells' work in bioethics is complemented by many years of clinical and teaching experience in respiratory therapy. She has a Diploma of Respiratory Therapy (1985) from the School of Respiratory Therapy in Halifax, an Honours B.A. (1994) in Philosophy with First Class standing from Saint Mary's University, an M.A. (1996) and Ph.D. (2000) in Philosophy with concentrations in medical ethics from the University of Tennessee.

Dr. Ells coordinates activities under the Cooperative Venture in Health Care Ethics, Law and Policy, a partnership program between Dalhousie University's Department of Bioethics and Health Law Institute with the IWK Health Centre, Queen Elizabeth II Health Sciences Centre, and the Nova Scotia Hospital.

Dr. Ells' research interests include organizational ethics, health policy, the intersection of autonomy and chronic impairment, and feminist ethics. Published work on these topics can be found (or is forthcoming) in, *Journal of Medicine and Philosophy*, *Journal of Medical Humanities Social Theory and Practice*, *Healthcare Ethics Committee Forum*, *CMAJ*, *Healthcare Management FORUM*, *American Journal of Bioethics*, and elsewhere. Dr. Ells also presents her work regularly at national and international meetings.

Dr. Ells is a member of the Social Sciences and Humanities Research Ethics Board at Dalhousie University, Clinical Ethics Committee at QEII Health Sciences Centre, Assisted Reproduction Advisory Committee at IWK Health Centre, and Steering Committee for the Maritime Hereditary Cancer Program at Cancer Care Nova Scotia.

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For further information on the Health Ethics, Law and Humanities Peer Review Panel please contact:

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