

Canadian Bioethics Society

NEWSLETTER

Volume 11, Number 1

February 2006



PRESIDENT'S LETTER

Bernard Keating 2005-2006

Do you visit your website?

The Society's new website has been up and running now for more than one year! Not only does it serve as a tool to better expose bioethics and the Canadian Society of Bioethics, but it also serves as a valuable communication tool for us.

I encourage you to participate to make the website your own by making suggestions on its content so that it will better meet your needs and by visiting it regularly to keep up on what is going on in your Society. This way, you will be up to date on the Society's priorities and on the status of projects.

Since the site's remodeling, we have decided to maximize the direct and instantaneous communication potential offered by a website. For this reason, you will be able to share your opinion and thoughts about current projects on the website. The website is in fact a tool that allows to continue conversations throughout the year between the executive and the general meeting...

The *Bioethics Canadian* Review project

This project, driven by Ian Mitchell, has been discussed at the last two annual general meetings. Last October, in Halifax, the executive had been

asked at the general meeting to continue the discussion and to set a course of action. We then committed to include the work document prepared by Ian Mitchell and Sue Genest

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Canadian Bioethics Society NEWSLETTER

Charitable Registration #0876649-09

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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.

Acceptance of a submission or advertisement does not constitute CBS endorsement or necessarily represent the official viewpoint of the Society. All reproduction rights are reserved.

Next Issue's Submission Deadline – May 15, 2006

Advertising Rates

\$50/half page

\$100/full page

No charge to CBS institutional members

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President's Letter – continued from page 1 ...

to the website to fuel the discussion and to obtain reactions.

All opinions are received with great appreciation. We thank those who accepted to participate with this subject. The discussion held at the meeting allowed for an open exchange where all opinions are welcomed. I believe that reservations, when voiced, are much more valuable than muttered approvals or circumstantial assents... They usually indicate the roadblocks that will need to be addressed if the project is to be a success! Rest assured that we consider your responses with the greatest care. We count on you to improve this project and ensure its success.

More to follow on <http://www.bioethics.ca>.

Developing a vision for the CBS's future

Sue McRae agreed to pilot this project and to let the Society take advantage of the experience she gained in this type of work at the University of Toronto's Center for Bioethics. The society was founded in 1988, over fifteen years ago! Bioethics has evolved, its teachings have spread, its practice has changed, and new generations of bioethicists have joined the first generation who had given the society its priorities and orientation. The daily reality of health care has also evolved, the health system is at the heart of debate, and research ethics has known an ever increasing interest, taking center stage. All those/ these factors are motivating us to start a process where we will have to develop, together, a vision for the Society's future. What do we want the Society to look like in 5 or 10 years? Your participation is essential. It is not the executive's role to decide about the Society's fundamental orientations — it is your role!

More to follow on <http://www.bioethics.ca>.

Bernard Keating Ph.D.

CBS WORKING CONDITIONS FOR BIOETHICISTS TASKFORCE

By Co-Chairs Paula Chidwick, PhD and Eoin Connolly, MA

At the October 22, 2005 CBS Annual Meeting in Halifax, the Taskforce met to present on their activities and findings from the past year. The Taskforce consists of the following members: Jennifer Bell, Paula Chidwick, Eoin Connolly, Michael Coughlin, Andrea Frolic, Laurie Hardingham, Christine Harrison, Chris MacDonald, Pat Murphy, Dawn Oosterhoff, Paddy Rodney, Randi Zlotnik Shaul and George Webster.

Background

Increasingly hospitals, long-term care facilities and private clinics, as well as health insurance, biotech and pharmaceutical companies, are hiring bioethicists to provide ethics education, policy analysis and case consultation. Asking contentious ethical questions, and articulating “buried” issues are commonplace to the role of the bioethicist. Thus, bioethicists are particularly vulnerable to conflicts with their employers. How can bioethicists foster a

mutually respectful relationship with their employers and best safeguard their integrity as professionals? The CBS Working Conditions for Bioethicists Taskforce was created by the Executive of the CBS to address some of the practical issues along the continuum of a bioethicist’s career. Members of the committee presented their work to date on four projects. The goal of the session was to inform CBS members of the Taskforce’s work and to solicit feedback on its various projects. The following provides a brief outline of the presentations at the CBS Halifax Annual Meeting.

A PILOT QUALITATIVE STUDY OF CONFLICTS OF INTEREST AND CONFLICTING INTERESTS AMONG BIOETHICISTS IN CANADA

Andrea Frolic, Ph.D and Paula Chidwick Ph.D

This study collects stories from bioethicists in Canada who have experienced conflicts of interest

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Mark Your Calendar Now!

Canadian Bioethics Society Annual Meeting

and

3rd International Conference on Clinical Ethics Consultation

~ 2007 JOINT CONFERENCE ~

Toronto, Ontario, Canada

18th Canadian Bioethics Society Conference

Wednesday, May 30, 2007 – Friday, June 1, 2007

3rd International Conference: Clinical Ethics Consultation

Friday, June 1, 2007 – Sunday, June 3, 2007

Location: Toronto Marriott Downtown Eaton Centre

Host: Joint Centre for Bioethics University of Toronto

~ Exciting Details to Follow in Upcoming Newsletters ~

and/or conflicting interests with their institutions. The goal of this research is to explore the social, political and personal dimensions of professional conflicts of interests and/or conflicting interests for bioethicists in Canada through in-depth interviews with bioethicists who have personally experienced such conflicts. The stories collected will be amalgamated into 2-4 paradigmatic case studies. These case studies will be composite accounts that illustrate the convergent themes and issues identified in the analysis of all the narratives. The session presented preliminary data on the function and role of ethicists, the nature of the conflict of interests, the types of conflicts of interest and the experiences of conflicts of interests among bioethicists in Canada. Data is still being collected and volunteers for this study should contact Andrea (frolic@hhsc.ca) or Paula (paula_chidwick@oslerhc.org) before March 31, 2006 to participate.

MODEL CONTRACT

Dawn Oosterhoff, RN, SJD and Eoin Connolly, MA

The Model contract for bioethicists attempts to provide the foundation for a transparent relationship between bioethicists and their employers. It follows from previous discussions on this issue published in the February 2000 CBS Newsletter: "Employment/Disemployment Conditions for Clinical Ethicists" by Michael Coughlin and "Questions to ask about a job as a Bioethicist" by Christine Harrison, and from the initial document on the topic from Chris MacDonald and other members of the Taskforce (<http://www.bioethics.ca/workingconditions.pdf>). In drafting the model contract we surveyed the literature, and put a call out to Taskforce members, the Medical College of Wisconsin Bioethics listserv and other colleagues to submit their contracts or letters of agreement, and asked Taskforce members to submit their top five issues/clauses that should be included in a contract template. The Model Contract covers job description, duties, budget, public statements, and academic freedom, property of publication, emperor's clause, confidentiality, accountability, reporting relationships and protected research time. Working Conditions covered include

accessibility, salary, vacation, office support and professional fees. The model contract should be available on the CBS website by the end of 2006.

PEER SUPPORT

Laurie Hardingham, RN and George Webster, PhD

In several cases bioethicists in Canada and the U.S. have found themselves in extremely difficult situations as a consequence of taking a particular position or stand on a controversial issue or question. Some have lost their jobs, some have been threatened with losing employment and others have faced threats of harm or violence because of their views. Bioethicists, as part of their jobs, must be able to raise uncomfortable and/or unpopular questions for discussion and consideration, and may need support to do this. In many circumstances, bioethicists may have few supportive colleagues nearby to turn to for support, or with whom they could explore conflicts or difficulties. Peer Support for bioethicists would offer a process for colleagues to access third party assistance or advice needed in circumstances where bioethicists feel they have compromised themselves, are being compromised, or are being put in difficult ethical situation by their organizations. This session discussed the definition and role of Peer Support, when and how it would be accessed, the benefits and outstanding questions.

DISPUTE RESOLUTION MODELS

Chris MacDonald

Further developing the Peer Support Model presented by Laurie Hardingham and George Webster, Chris MacDonald outlined a variety of dispute resolution models. The CBS could potentially provide peer support through individuals or panels, the services of a lawyer, neutral evaluation, a "grievance" mechanism (as in unions), "expert" impartial mediation, and arbitration. Each option was discussed in detail including potential benefits and infrastructure requirements. The possibility of a CBS policy on this issue was discussed to address who could access this process and who is qualified to serve as a counselor.

CBS 2005 ANNUAL AWARD RECIPIENTS

Once again, the highlight of the Annual General Meeting of the CBS was the presentation of the awards for Distinguished Service, and for Lifetime Achievement. Dr. Nuala Kenny received the former award, and Dr. Hubert Doucet was the worthy recipient of the latter.

Dr. Kenny's award was particularly timely, as she was chair of the organizing committee for the Halifax Conference. Hence all in attendance got to experience first hand her dedication and enthusiasm for her work. Dr. Kenny has been a tireless crusader for bioethics in Canada, and has been an enthusiastic supporter of the CBS over the years, including a term as president.

Dr. Doucet has been a stalwart for bioethics in Quebec, Canada, and internationally over the years. The high regard in which he is held by his colleagues and students, and the deep affection and admiration they feel toward him, was evidenced by the enthusiastic response he received from the Quebec cohort when Dr. Bernard Keating presented him with the award. Professor Doucet gave a brief reflection on his experience in bioethics, and on his views of the future of bioethics in Canada and abroad.

The CBS is pleased to honor Dr. Kenny and Doucet in this manner. We look forward to the meeting in 2007, and the opportunity to recognize the significant contributions of other outstanding members of the Canadian Bioethics Society.

Canadian Bioethics Society / Société canadienne de bioéthique

CALL FOR NOMINATIONS

The Canadian Bioethics Society is accepting nominations for two awards in recognition of those who have made significant contributions to health care ethics in Canada.

LIFETIME ACHIEVEMENT AWARD

The CBS Lifetime Achievement Award is given annually to an individual whose demonstrated scholarship and/or leadership has contributed significantly to health care ethics in Canada. Any member of the CBS may nominate an individual for the award. Nominees need not be members of the CBS.

Criteria for selection include:

- A clear focus on health care ethics in his or her lifetime achievements
- National and international profile in health care ethics
- Outstanding leadership in shaping the field of health care ethics in Canada
- Primary consideration will be given to nominees whose major contributions have occurred in the Canadian context

CBS DISTINGUISHED SERVICE AWARD

The Distinguished Service Award recognizes outstanding and dedicated service to the Canadian Bioethics Society. Any member of the CBS may nominate an individual or group for the award.

Criteria for selection include:

- An individual or group that has advanced the mission of the CBS in a significant and lasting manner.

Submission and consideration process

Nominations for either award should be in the form of a letter demonstrating how the nominee matches the stated criteria. At least three letters of support should accompany the nomination. The final decision will be made by the Awards Committee and will be based on the stated criteria. If, in the opinion of the Committee, there are no nominees who fit the criteria, the Committee may decline to make the award in any given year. Only one nominee will be chosen in each award year. The awards committee will reconsider nominees from previous years, if it is notified in this regard. New letters of nomination and support will not be required, however updated information is welcome. The deadline for nominations for the 2007 awards is October 31, 2006.

The award recipients will be determined by the awards sub-committee of the CBS Executive. This committee has six members, two of whom represent the Executive. Daryl Pullman, the Atlantic Canada representative, is the current chair. Presentation of the awards will be made at the annual general meeting of the society and the recipients will each be invited to make a major presentation at that time.

Please submit nominations and letters of support to:

Lydia Riddell, CBS/SCB, 561 Rocky Ridge Bay NW, Calgary, AB T3G 4E7



CBS STUDENT UPDATE

By Shannon Madden

2006 will be a great year for the students of CBS/SCB! My vision for 2006 is to see the student body continue to grow and prosper. With a lot of things on the go, and our student networking increasing, this vision is not far from being realized.

A year in review:

- ★ In 2005 the **university rep program** grew from 14 students representing 10 Canadian universities to 23 students from 16 Canadian and international universities and as well as representation from other ethics programs! University reps act as a 'hub' for our society. They are both local liaisons and contact points for students within their universities and students from across the country seeking information about CBS/SCB and about bioethics programs at their school. I would like to thank all of the reps for their continued dedication to this endeavor. The list of current reps is provided below, but check the website often for additions and changes. If you would like more information on how to become a university rep, contact me. My goal is to have a rep from every university/school that offers bioethics training by 2007!
- ★ It was great seeing so many students at the **17th annual conference**. This year we blew the roof off previous attendance, with 69 student participants from across the country, and internationally. I must give thanks to Catherine MacPhearson, Ryan Melnychuk and their hard working team – all of the conference events were a success! We'd also like to thank the Society for its continued support of student activities. This of course includes the annual abstract competition. Congratulations to the 2005 winners: Jennifer Bell, Matthew Herder, Marianne Dion-Labrie,

Natalie Ram, Marika Warren, Jonathan Lear, Nina Preto, and Fiona MacDonald. The next abstract competition will be for the 18th annual conference to be held in the spring of 2007.

- ★ The **Annual Student Business Meeting** was held at the conference. We have started discussions around the definition of a student. Currently the definition is: "Undergrad/grad students who do not hold a terminal degree" (from October 13, 2001). The student group talked about keeping this definition for the purpose of the abstract competition; however it was suggested to make an amendment for membership and conference registration purposes to "student & trainees" to allow PDFs and RAs the lower fees. The benefits of being a student member include a lower conference registration fee, access to the student abstract competition and in 2007, access to the travel bursary (more info below). If you have any feedback or comments on this, please let me know.

Things to look forward to in the year ahead:

- ★ The **18th annual conference** will be held in the spring of 2007 in Toronto (my home town!). I am looking forward to welcoming you all to the city. It may feel like a while off, but keep it in mind as you work on your research – the abstract competition will be announced through email and through the newsletter. If you would like to help with the planning of the conference, please let me know; we will need individuals to help with local planning, as well as the abstract competition. ****New for the 2007 conference:** as a trial, students will have the opportunity to apply for travel bursaries; more information will be available closer to the conference.

★ The **3rd Canadian National Undergraduate Bioethics Conference** will run February 16th-18th, 2006 at the University of Lethbridge. More information and on-line registration is available: <http://www.canadianbioethics.ca/3rd>

★ CBS/SCB is continuing to work towards the collaboration of the **AMS Studentship**. The plan is to co-host the studentships award. Winners are funded for 4 months work over the summer in the area of bioethics. Ten awards of over \$4000 are given each summer. This is the first step

towards offering more student awards. Check the website and your email as this develops!

It continues to be an honour for me to represent the student body on the Executive. As you can see, the students of CBS/SCB have a lot to be excited about – my hope is that you too have an exciting year and that you are a part of our excitement! If you have any issues, questions or concerns, please contact me. If you would like to be informed of up-to-date student issues, please send me your email and I will add you to the list!

University Representatives:

School	Contact	School	Contact	School	Contact
UBC	Holly	UofT	Shannon	McGill	Anais
UVic	Morgan	UofT	Diego	UMontreal	Josee
UVic	Lorelei	Western	Pat	UMontreal	Nathalie
UofAlberta	Amy	York Univ	Leah	UMontreal	Lisa
UofCalgary	Nina	McGill	Emily	Dalhousie	Meredith
McMaster	Shail	McGill	Shawna	Midwifery	Ainsley
Queens	Erin	McGill	Gillian	NewZealand	Pat
Queens	Nir				

Mark Your Calendars

**Plan now to attend the
18TH ANNUAL
CANADIAN BIOETHICS SOCIETY
CONFERENCE**

May 2007

Hosted by
The University of Toronto Joint Centre for Bioethics

Concurrently with
The 3rd International Conference in Clinical Ethics

STUDENT WORKS

FATHER FIGURES: PATERNALISM OF PHYSICIANS IN THE NOVEL, DRACULA

Suzanne Ronald, B.Sc.

Medical Student, Year 1

MSc Candidate, Section of Neurosurgery

Department of Surgery, University of Manitoba

D*racula*¹, published in 1897, is one of the greatest horror stories in English literature. As with the AIDS and hepatitis C viruses in our own time and syphilis during the novelist's, the vampiric cult has emerged during periods of strangely spreading infection and disease. Bram Stoker died at the age of sixty-four on 20 April 1912, quite possibly, according to his grand-nephew Daniel Farson, of complications from tertiary syphilis². Whatever his motivations, Stoker constructed, to terrifically unsettling effect, a Hungarian vampire who visits England and initiates one of the novel's heroines and whose makeup is defined by an unpredictability that can be temporarily combated by the methods of science. In threatening to infect the country with a virulent sense of perversity, Dracula, described by Dr. Seward as 'the father or furtherer of a new order of beings, whose road must lead through Death, not Life' (p.251), therefore demoralizes the metaphysical views of the novel's England; the belief in a world created by God and governed by rational laws. This essay will discuss how paternalism of physicians in the novel, *Dracula*, leads to a utilitarian approach to medicine and *strikes at the heart* of the doctors' moral and positivist principles.

In illustrating new questions of the material universe, *Dracula* embodies the cultural dynamics at play which were beginning to undermine the hierarchical, class-structured society that empowered propertied men at the expense of all other groups, vulnerable or otherwise. Forces of impending social change such as romanticism, democratic theories, feminism and the rights of individuals (or rights of patients, for our purposes), all in their own ways, were beginning to buttress the validity of individual experiences and intuition instead of the ideals of eighteenth-century rationalism and nineteenth-century utilitarianism and positivist theories.

Although rumored to be gay³, Stoker appears to offer a misogynistic, as well as xenophobic, reaction against the concept of sexual continuum. His creation of Dracula – a selfish and dandified anti-bourgeois, broadly aligned with qualities traditionally

considered feminine in the 19th century (red lips, excess of imagination and a lack of sufficient reason) – is finally driven from England and conquered by a group of 'manly' men. These men hold a host of professions and social roles, and cooperatively they represent the medicinal powers of traditional patriarchal rule and its concomitant metaphysical world-view. There is the solicitor Harker; the psychiatrist Dr. Seward, whose psychotic patient, Renfield, is possessed by Dracula; there is the aristocratic, Lord Godalming; there is the American Quincey Morris, and spearheading the group is Dr. Abraham Van Helsing (carrying Stoker's given name) who, as a medical doctor, a doctor of philosophy and literature and a knowledgeable paralegalist is Dracula's opposite and double, at least in many overt ways. These men collectively overcome Dracula with their rationalism, utilitarianism and scientific methodology.

Dracula is a compilation of first-person accounts of events, among which are journal and diary entries kept by the principal characters, letters, newspaper articles, ships' logs and patient interviews. All of these first-person narratives rest upon the assumption, largely agreed upon by nineteenth-century positivists, that reality conforms to that which we observe and record, and consequently words derive their meanings from a natural, inherent link with the material world. Stoker's narrative strategy appears to confirm further the traditional Victorian ideology implicit in the success of Van Helsing's men in first understanding the whereabouts and movements of Dracula, then tracking him down and destroying him. A consequentialist would argue this was a success, although success required lying, deception, breaking and entering, and a personal cost to the doctors' system of beliefs that would seem to turn success on its ear.

Paternalism of physicians, particularly when dealing with vulnerable patients, conflicts the ethical principles of beneficence and respect for autonomy^{4,5}. An arresting, perhaps even pervasive, irony compromises the actions of Dr. Van Helsing and Dr. Seward. The transfusions for Lucy, which are all done without her consent, all fail. Not even collectively can their attempted reversals of Dracula's influence save her in the end. What Van Helsing refers to as 'the grim irony of it all' attends their joint efforts of restoration (p.146). Today, patient participation in medical care and in decision-making is generally viewed as a precursor to positive health outcomes⁶.

Some ethics specialists would argue that while the patient is an expert in the hermeneutic sense – they alone experience their illness – there is a risk of confusing experience with expertise⁷, and that physician responsibility should be favored over patient responsibility⁸. In this case, however, the physicians not only change Lucy, without her knowledge or consent, into the very figure of perversity they are trying to fight off, but in so doing they subvert their own moral position. This is evident when Lord Godalming discloses his belief that he has consummated his relationship to his fiancé,

Lucy, through a blood transfusion, although unknown to him the doctors' have already given her their own blood in transfusions which failed to restore her. Dr. Van Helsing illustrates their chagrin by reflecting: 'Then this so sweet maid is a polyandrist, and me, with my poor wife dead to me, but alive by Church's law, though no wits, all gone – even I, who am faithful husband to this now-no-wife, am bigamist.' (p.146).

An equally disturbing irony also characterizes Dracula's attack on the other heroine, Mina. In wishing to protect Mina, Van Helsing and his men exclude her from their actions, although she is the first to learn the secrets of the journals of others. Until this point in time, the entire team had been kept in the dark by the doctors as to the diabolical features of Dracula. The reason for excluding Mina is specifically that she is female and so unsuited to the stress and offensive actions required, or to the discussions pertaining to them. Consequently, Mina lies sleeping defenceless during Dracula's attack, for her would-be guardians are simultaneously searching for the Count at 'Carfax', his London hideaway. The need to re-establish traditional patriarchal dominance again leads to the very thing these men wish to prevent and results in the confounding of their moral and positivist principles.

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1. Bram Stoker. *Dracula* (Wordsworth Editions Limited, 1993)
 2. David Rogers. "Introduction" *Dracula* (Wordsworth Editions Limited, 1993)
 3. David Rogers. "Introduction" *Dracula* (Wordsworth Editions Limited, 1993)
 4. Stephen R. Tee; Judith A, Lathlean. "Philosophical and Ethical Issues: The ethics of conducting a co-operative inquiry with vulnerable people." *Journal of Advanced Nursing* 47:5 (2004): 536-537.
 5. Dogan et al. "Informed Consent, Surrogate decision makers, conflict of autonomy and the paternalistic approach: A case report from Turkey." *Nursing Ethics* 8:6 (2001): Academic Search Elite Database.
 6. KH Jahng, et al. "Preferences for medical collaboration: patient-physician congruence and patient outcomes." *Patient Education Counselling* 57:3 (2005): 308-14.
 7. David Badcott. "The expert patient: Valid recognition or false hope?" *Medicine, Health Care and Philosophy* 8:2 (2005): 173-178.
 8. M. Kelley. "Limits on Patient Responsibility." *Journal of Medical Philosophy* 30:2 (2005): 186-206.



**The 6th International Conference
on Priorities in Health Care.
September 20, 21, 22, 2006.**

**Theme:
*Real World Priority Setting***

Streams:

- Methods, Approaches and Knowledge Transfer in Real World Priority Setting
- Priority Setting for New Technologies
- Priority Setting in mixed Public and Private Systems
- Values in Priority Setting
- Priority Setting and the Interaction between the Micro and Meso levels

It is our distinct pleasure to invite you to the **6th International Conference on Priorities in Health Care**. No matter what your background you will find that Toronto '06 will be an exhilarating and stimulating opportunity to share experiences and cutting-edge innovations and network with a community of world leaders from over 80 countries who are shaping priority setting practices locally and globally.

The theme of this year's conference is ***Real World Priority Setting – Shaping priority setting around real life innovative practices***. This conference is a vital element in the development of modern health systems. Priority setting directly determines the sustainability and quality of health systems, locally, nationally and globally. Moreover, priority setting decisions create and support either equity or inequity, justice or injustice. This is a crucial 'moment in time' to build on past learning and forge innovative improvements in real world priority setting contexts — for the good of all the world's people.

Deadline for Abstracts: March 1, 2006

Deadline for Early Registration: June 15, 2006

For more information and to register see:

www.healthcarepriorities.org

MONTREAL
JUNE 4-7, 2006



GENOMICS & PUBLIC HEALTH

4TH INTERNATIONAL DNA SAMPLING CONFERENCE
CHAIR: BARTHA MARIA KNOPPERS

PROGRAM OVERVIEW

Sunday, June 4th 2006

Keynote Address: Francis S. Collins (USA) "Genomic Medicine: Opportunities and Responsibilities" and Opening Reception

Monday, June 5th 2006 - NEWBORN SCREENING REVISITED

I - EXPANSION OF SCREENING? Chair: Gerard Loeber (Netherlands)

Speakers: Bridget Wilcken (Australia) "Expansion of Newborn Screening: Current Achievements and New Prospects"; Nikki Kerruish (New Zealand) "Newborn Screening for Genetic Susceptibility: What's the Harm?"; Anne Marie Comeau (USA) "Newborn Screening: The Massachusetts Model for Surveillance Research"

II - NEWBORN SCREENING: CARRIER STATUS? Chair: Wylie Burke (USA)

Speakers: Helena Kääriäinen (Finland) "Carriers Detected by Neonatal Screening: A Clinical Geneticist's View"; Jean-Louis Dhondt (France) "Lessons from Sickle Cell and Cystic Fibrosis: France"; Lainie F. Ross (USA) "Lessons from Sickle Cell and Cystic Fibrosis: USA"

III - NEWBORN SCREENING: STORAGE AND ACCESS FOR RESEARCH? Chair: Ellen Clayton (USA)

Speakers: Jeffrey R. Botkin (USA) "Ethical and Social Considerations in Research with Stored Bloodspots"; Bent NØrgaard-Pedersen (Denmark) "The Danish Newborn Screening Program: Routine and Research Uses"; Denise Avard (Canada) "Research and Surveillance in Canada"

Tuesday, June 6th 2006 - PUBLIC HEALTH GENOMICS

I - TOWARDS PUBLIC HEALTH GENOMICS: Chair: Melissa A. Austin (USA)

Speakers: Ron Zimmern (UK) "What Is it and Why Is it Important?"; Angela Brand (Germany) "Challenges for Public Health Genomics"; Anne Cambon-Thomsen (France) "Normal Human Genomic Variation and Public Health"

II - STATE POWERS AND PRIVACY: Chair: Timothy Caulfield (Canada)

Speakers: Mark A. Rothstein (USA) "Privacy Considerations in Public Health Genomics"; Darren Shickle (UK) "Balancing Private and Public Interests in Policy"; Ruth Chadwick (UK) "State Powers and State Responsibilities?"

III - IMPLEMENTATION IN PUBLIC HEALTH: Chair: Ana Sánchez Urrutia (Spain)

Speakers: Muin J. Khoury (USA) "Genomics and Public Health in the United States"; Sian Griffiths (Hong Kong) "Mainstreaming Public Health Genomics: A Community Perspective"; Jane Halliday (Australia) "Implementing Population Screening Programs"

Wednesday, June 7th 2006 - CURRENT APPROACHES AND FUTURE PERSPECTIVES

I - THE ROLE OF INTERNATIONAL STAKEHOLDERS:

Chair: Abdallah Daar (Canada)

Speakers: Elettra Ronchi (OECD) "From Genomic Research to Public Health Practice: International Policy Implications"; Mylène Deschênes (P3G) "Public Population Project in Genomics"; Mohamed Karmali (GRAPH-Int) "Genome-Based Research and Population Health International Network"

II - THE ROLE OF CITIZENS IN PUBLIC HEALTH

GENOMICS: Chair: Michèle S. Jean (Canada)

Speakers: Hubert Doucet (Canada) "Genomics and Modes of Democratic Dialogue: An Analysis of Two Projects"; Caroline Hurren (UK) "Developments in Genomics: Engaging Young People"; Closing Keynote Address: Bartha Maria Knoppers (Canada) "Public Health Genomics: Responsibilities and Opportunities"

INFORMATION, REGISTRATION, ABSTRACT SUBMISSION:
WWW.HUMGEN.UMONTREAL.CA/EVENTS/DNASAMPLING

Canadian Bioethics Society

Executive Committee – 2006-2007

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