

# Canadian Bioethics Society

# NEWSLETTER

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April 2009



## PRESIDENT'S LETTER

Patricia (Paddy) Rodney, 2007-2009

### Finding Our Moral Compass in Health Care Delivery

*"Efficiency, or cost-effectiveness, has become an end in itself, a value more important than others" (Stein, 2001, p. 3)*

Janice Gross Stein's words are, perhaps, even more true today than they were eight years ago when her book, *The Cult of Efficiency* (2001), was published. As a political scientist who is an astute observer of our society's talk about two of our most fundamental public goods—public education and health care—Stein argues that our obsession with efficiency has largely trumped values of effectiveness and accountability.

Treating efficiency as an ends instead of a means has resulted in a health care delivery system that has, at least in part, lost its moral compass. For instance, acutely ill patients are often discharged from hospitals as quickly as possible, with the burden of care in the home falling disproportionately on family members, especially women (Health Council of Canada, 2008; Lynam et al., 2003; Peter, 2004). Health care team members in all arenas of practice are facing increasing work-

loads, illness, injury, and attrition (Aiken et al., 2002; Quality Worklife Quality Healthcare Collaborative, 2007; Shamian et al., 2002). Further, beleaguered health care team members have a difficult time engaging in constructive communication with each other, which hampers their ability to provide safe, competent, and ethical care (Baker et al., 2004; Canadian Health Services Research Foundation, 2006; Singer et al., 2009; Spence Laschinger & Leiter, 2006; Storch, 2005; Varcoe & Rodney, 2009). In other words, the values that ought to provide direction for health care delivery are difficult to operationalize in today's climate of fiscal constraint and concomitant overemphasis on efficiency. This is not to say that there are not many areas of strength and some progressive new initiatives in health care delivery. It is to say, though, that there is significant work to be done to return efficiency to its place as a means to serve values-based ends. This is especially

urgent in our current economic downturn, when there is a danger that values-based ends may become even further eclipsed.

Clinical ethics work has a significant role to play here. Our colleagues in the Canadian Bioethics Society (CBS) who support the ethical ... *continued on pg. 2*

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# Canadian Bioethics Society NEWSLETTER

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

practice of health providers, administrators, and policy makers are in a strategic position to keep values such as effectiveness, accountability, human dignity, compassion, and relief of suffering visible alive. Such work is enormously complex and enormously important in our current health care delivery systems (DeRenzo & Strauss, 1997; Kirby, Simpson, McNally, & McDonald, 2005; McPherson et al., 2004; Reiser, 1994). What does all this mean for the CBS? As you will note from the CBS Executive's report on our strategic planning (*CBS Vision 2012: Strategic Plan*) in this Newsletter, at this time in our history we are interested in promoting standards and guidelines that will provide more support for those of our colleagues who engage in clinical ethics work.

Of course, our strategic planning also addresses other areas. Our CBS membership includes a wonderful array of people from a variety of disciplines who engage in ethics work through research, consultation, education, and clinical practice in many facets of biomedicine and health policy as well as health care delivery. All have an important role to play in influencing the moral compass of Canada's scientific, health, and health care systems. The initiatives you read about in this Newsletter—and that you will learn more about (and participate in) if you come to our 20<sup>th</sup> Annual Canadian Bioethics Society Conference in Hamilton this June—offer great promise for our collective future.

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<sup>1</sup> 20<sup>th</sup> Annual Canadian Bioethics Society Conference, *Just Evidence*, June 11<sup>th</sup>-14<sup>th</sup>, 2009 Hamilton, Ontario <http://fhs.mcmaster.ca/bioethicsconference/>

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# REPORT FROM THE CBS EXECUTIVE COMMITTEE

The Executive Committee met for a retreat in Calgary in mid-February and is pleased to report it is working towards the goals arising from the “CBS Vision 2012: Strategic Plan.”

Some of the projects the Executive intends to focus on over the next two years include:

**Professionalization** – The Executive will continue to provide support for understanding and moving towards professionalization in bioethics, as well as peer support for clinical ethicists and others working in the field. The Executive will be working with the Task Force on Working Conditions for Bioethicists on the “Development of a Model Job/Role Description” and on a “Peer Support Network for Bioethicists” as part of the wrap-up of this group’s work. Please visit the website/newsletter for updated reports. The Executive also looks forward to supporting and working with “PHEEP: Practicing Healthcare Ethicists Exploring Professionalization.” This group will be exploring current opportunities and challenges related to the professionalization of health care ethics practice in Canada;

**Student Support** – The Executive actively supports student involvement in the CBS, but there is always room for more. Current plans are to update the website with more information and useful links for graduate and undergraduate students. The Executive is in the process of re-evaluating all of the student awards, with a view to the possible development of new ones. As the future of the CBS, ensuring that students receive the support, mentoring and encouragement needed will be essential!

**Regional Activities** – Supporting current and developing

regional activities in bioethics is seen to be important for the development of bioethics in Canada. This could involve support for ethics conferences in the different regions of Canada, providing more information to CBS membership regarding bioethics activities in their areas, involving/increasing the role of the Francophone bioethics community, and by acting as a communications medium for other information exchange between members. Keeping everybody up-to-date will help all of our members across Canada keep abreast of what is going on across the country;

**Networking** – CBS will look to develop new relationships and strengthen old one with groups such as the Neuroethics Group, the American Society for Bioethics & Humanities, Feminist Approaches to Bioethics, Health Technology Assessment, the Provincial Health Ethics Network (Alberta), the Nova Scotia Health Ethics Network and the International Association of Bioethics. This could be a great way to connect all of the work that is going on across Canada in a more systematic, meaningful way. This could also be a great way to share resources, connect professional ethics resources, provide access to consultation support, encourage research connectivity, provide ethics committee and research ethics board peer support, make sure our members have access to other opportunities, identify different ethics resources in Canada and the work they do (provincial resources, regional resources and Academic centre resources) and to connect with other organizations.

Please review the Newsletter and check the CBS Website ([www.bioethics.ca](http://www.bioethics.ca)) to learn more about the exciting new path down which the CBS is headed.

## CANADIAN BIOETHICS SOCIETY CONFERENCE 2010 IN KELOWNA, BRITISH COLUMBIA

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**8-12**

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## STUDENT REPORT



# EXCITING NEW STUDENT PROGRAMS AND CONFERENCE INFORMATION FOR STUDENTS

*By Meredith Schwartz and Gina Freeman*

**B**ig and exciting changes are happening at the SCB-CBS! We have finished the visioning process, and this February the SCB-CBS executive met to evaluate the programs we already have, and to discuss how to further implement goals of the visioning process. Some of these new programs are directly related to students, and all of them will be of interest to students.

Gina and Meredith met together to discuss the student programs, the student website, and ways to continue the programs that are working while improving and building on them for the future. It was great working together, since brainstorming as a pair is much more fruitful than brainstorming alone. Gina and Meredith are currently writing up proposals for new student awards and new methods to increase student funding to support conference attendance. We have also looked at possible improvements to the student SCB-CBS website so that it will be more useful for students. We are looking to develop better communication with students to attract them to bioethics and get them involved in the SCB-CBS. We are beginning to consider means of facilitating student networking with other students and with professional mentors to support bioethics education and to help students navigate the (sometimes mysterious) paths through an education in bioethics. If you are interested in learning more about these proposals, and you would like to have some input in their development, we invite you to the discussion at the Student Business Meeting on Friday June 12, 2009 from 7:30-8:30 AM at the 20<sup>th</sup> annual SCB-CBS conference in Hamilton. We really hope that you will attend: although brainstorming as a pair is better than alone, when we have a group of the energetic students that make up the SCB-CBS thinking about programs together it will surely be even more productive!

Speaking of the 20<sup>th</sup> annual SCB-CBS conference, the 2009 conference "Just Evidence?" in Hamilton, Ontario (June 11-14) and the preconferences (June 11) are approaching quickly. I would like to introduce you to Lucy Langston, she can be reached at the email for SCB-CBS Student programs: [studentscbs@gmail.com](mailto:studentscbs@gmail.com). She is a master's student at McMaster University's Department of Philosophy and the Chair of the SCB-CBS McMaster Student Conference Committee. If you have any

questions about student accommodations in Hamilton or student events at the conference, then Lucy is the best person to ask. I would like to thank Lucy for all the work she has put into organizing the conference to ensure it is interesting and accessible to students. This year's conference is sure to be a big success because of her continuing efforts, and the efforts of the members of the student committees.

The conference website [http://fhs.mcmaster.ca/bioethics\\_conference/](http://fhs.mcmaster.ca/bioethics_conference/) is now up and running. The student page has details about the student activities, competitions and programs. This webpage will be updated continuously with the most current information, so be sure to check the website as the conference approaches!

**STUDENT ABSTRACT COMPETITION:** This year there were 50 excellent abstracts submitted to the student abstract competition, which made the selection of only 7 abstracts extremely difficult. We tried something new this year by matching the topic of the abstract to the reviewer's area of expertise. This resulted in more even evaluations, but it was also a lot more work for the chair of the student abstract committee, Kiran Pohar Manhas. We owe a special thanks to Kiran this year for the extra effort she put in to ensure that the abstracts were matched to reviewer expertise.

I would also like to thank the members of the student abstract committee: Tamara Adler, Stephane Ahern, Camille Assemat, Emily Bell, Renaud Boulanger, Samantha Copeland, Michael Da Silva, Simona Efanov, Nathalie Egalite, Olusegun (Segun) Famure, Cynthia Forlini, Jonathan Lear, Patricia Mariller, Ghislaine Mathieu, Diego Silva, Maxwell Smith, Raphaëlle Stenne, Scott Stevens, Mark Weir, McFee Yang, Amélie Zonato. We would like to say an extra special thanks to Samantha Copeland, Scott Stevens, and Mark Weir who were willing to take on extra work to ensure the abstracts were reviewed in time. This year the student abstract competition awards go to:

**Jason Behrmann**, Université de Montréal

**Isabelle Chouinard**, University of Calgary

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**Michelle Cleghorn**, University of Toronto

**Julie Cousineau**, Université de Montréal

**Cynthia Forlini**, Institut de recherches cliniques de Montréal

**Spencer Hey**, University of Western Ontario

**Danaë Larivière-Bastien**, Université de Montréal

Come out to the student business meeting on Friday June 12, 2009 from 7:30-8:30 am at the 20<sup>th</sup> annual SCB-CBS conference in Hamilton to meet these students and congratulate them as they receive their awards.

**STUDENT TRAVEL BURSARY PROGRAM:** This year we will be continuing the travel bursary program. There are eight travel bursaries available for students, but last year we only received four applications, so every student who applied was awarded a bursary! It is worth your time to apply! If you are interested in chairing the travel bursary committee or volunteering to referee the student travel bursary competition, please contact Meredith by email as soon as possible. Refereeing the travel bursary program does not preclude submitting an application.

The travel bursary program is intended to provide financial aid to students who wish to attend the SCB-CBS conference in Hamilton, Ontario. Travel bursaries are not limited to those presenting a paper or poster at the conference, but are instead open to any student who wishes to attend the SCB-CBS conference. You must attend the conference in order to qualify for funding. Those who are awarded a travel bursary will receive their cheque at the student business meeting on Friday June 12, 2009 from 7:30-8:30 AM at the 20<sup>th</sup> annual SCB-CBS conference in Hamilton.

The bursaries will be awarded to students based the student's ability to demonstrate that the SCB-CBS conference will be of benefit; distance traveled to attend the conference; and demonstrated financial need. Travel bursary applications must be submitted by email to [studentscbs@gmail.com](mailto:studentscbs@gmail.com), on or before the **April 30<sup>th</sup> 2009** deadline. Please see the conference website's student page for the application form and more information about the Travel Bursary program.

**VOLUNTEERING AT THE 20<sup>TH</sup> ANNUAL SCB-CBS CONFERENCE IN HAMILTON:** There are a few volunteer positions available from the CBS executive. The CBS executive will pay the registration fees for the chosen volunteers. The intent of the CBS volunteer program is to help make the conference more accessible to a larger group of students. Volunteers will be chosen based on their proven involvement with the CBS student group, and demonstrated financial need. If you are interested in volunteering for the conference, please send me an email at [Meredith.schwartz@dal.ca](mailto:Meredith.schwartz@dal.ca)

**STUDENT EVENTS AND FUNDRAISING:** We are planning some fun and interesting student events for this year's conference:

*T-Shirt Sales* – We will continue the student fundraising efforts by selling CBS t-shirts throughout the conference. If you would like to volunteer to help sell the t-shirts please send Meredith an email (see above description for more details).

*Student Meet & Greet* – The student meet and greet will take place between registration and the opening keynote address by Maude Barlow. The relaxed atmosphere of a local bar with light nibbles provides a great time to get to know other students attending the conference. (Thursday June 11, 2009 5:30-7:00 PM Location TBA)

*Student Business Meeting* – The visioning process is complete, and it is now time to implement the agreed-upon goals. This means an opportunity to advance student programs and student concerns. It is vital to hear your ideas and input! Come out to the business meeting and help us involve students in developing the future of Canadian bioethics. The Graduate Student Representative elections will be held at this time. (Friday June 12, 2009 7:30-8:30 AM Location TBA).

*Student Mentor Breakfast* – This breakfast provides an opportunity to chat with prominent bioethicists over coffee and croissants. You can discuss current issues, research, careers and more. More information will be available to you (including a list of mentors) once you have registered keep an eye on the student conference webpage for more details as the conference date approaches. (Saturday June 13, 2009 7:30-8:30 am Location TBA).

*Student Evening Social* – The final night of the conference will feature an affordable dinner at a local restaurant, followed by drinks. This event provides a relaxed time to get to know other students interested in bioethics. This is separate from, and more affordable than, the main social event which takes place on the Friday night at the Royal Botanical Gardens. Vegetarian options will be available. (Saturday June 13, 2009 7:00-10:00 PM Location TBA)

The conference website will have more details about these events as the conference approaches, so please keep an eye out for this information.

**UNDERGRADUATE UPDATE:** Come to the Canadian Bioethics Society Annual Meeting taking place this summer in Hamilton! Highlights for undergraduate students at this year's conference include the **Student Meet and Greet** (a great place to meet other students interested in bioethics, many at the graduate level), and the **Student-Mentor Breakfast** (where you can strike up a conversation with an established bioethicist over

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coffee). Get there in style with the **Student Travel Bursaries** offered by the Canadian Bioethics Society.

Currently, Meredith and I are working on programs to help engage undergraduate students in the Canadian Bioethics Society. The proposed programs are created with the aim of enriching the undergraduate experience.

One such proposal is a symposium to showcase the many diverse paths that can lead to a career in bioethics. The symposium will feature presentations about bioethics education and employment, and will be a great place to learn about your future possibilities in bioethics.

Other proposals aim to make participation in CBS and the annual meeting more affordable for undergraduate students. Students will be able to apply for awards that are specifically aimed at undergrads and membership costs will be reduced for undergraduate students interested in being members of the Canadian Bioethics Society

If you are interested in these programs, and if you have questions, comments or ideas of your own, come to the student business meeting at the CBS Annual Meeting and let your voice be heard!

### **GRADUATE STUDENT REPRESENTATIVE POSITION:**

Meredith's term as graduate student representative is ending and we are seeking an energetic and enthusiastic graduate student rep for the 2009-2011 term. The graduate student representative works with Gina Freeman, the undergraduate student representative, to coordinate student programs. Since the SCB-CBS is currently expanding some student programs, this is sure to be an exciting time to be the graduate student representative! The graduate student rep participates in all Executive meetings, teleconferences, serves on sub-committees as required and submits a student update report twice a year for submission in the Newsletter.

Elections for this position will be held at the student business meeting on Friday June 12, 2009 7:30-8:30 AM at the 20th Canadian Bioethics Society conference.

A valid nomination requires that the candidate submit a short (less than one-half page) biographical sketch on the official nomination form, indicating interests and background, along with a letter of agreement to stand. The deadline for nominations is April 1, 2009.

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Gina Freeman  
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## Clinical Ethics Summer Institute | CESI

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**For further information, please visit our website or contact:**



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# STUDENT SUBMISSIONS

The CBS Newsletter is pleased to present three articles written by students in this issue. These student authors would welcome comments and compliments on their submissions. The student's contact information is given at the end of each article.

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## The Growing Popularity of 'Grey-Area' Drugs

Just prior to the holiday season, I encountered a troubling situation. While working through the throng of holiday shoppers along the streets of Montréal, I decided to make a quick purchase at a popular chain of Québec convenience stores. There, in plain view next to the cash register, was a new bright and colourful display shelf, containing rows of individual packets of some indiscernible product. Intrigued, I moved in for a closer look.

Printed on each set of packets were silhouettes of characters, such as a meditating Buddha, well dressed men or women with hearts emanating from their bodies, and a break-dancing young adult, among others. No, this collection of products, distributed by HVL inc. ([www.radioenergie.com/dose](http://www.radioenergie.com/dose)), are not a new type of candy or pop-culture trinket. Rather, they are an assortment of stimulant drugs and supplements.

Each packet, containing two pills (which are visible), declares that these products are 'all natural', and depending on the product, contain substances that are effective in countering a variety of problems including the recovery from a hang-over, fatigue, or low sexual desire. In other words, these pills are a collection of readily affordable (\$2.99/packet) stimulants, multivitamins, plant extracts, and supposed aphrodisiacs. Oddly, the stimulant product (called 'Boost') claims to promote cardiovascular health as well. I was alarmed and angered by the thought that this new class of drugs would be available at convenience stores across the province.

### CONSUMER DECEPTION AND RISKS TO VULNERABLE POPULATIONS

Aside from the fact that some of these products are obvious frauds (I doubt that actual hang-over remedies and aphrodisiacs would be sold at less than 3\$ a pop – and to my knowledge, there's no scientific evidence for either!), the precedence of retailing drugs in corner stores is unusual and arguably unethical. For one, it encourages the consumption of pills and makes them widely accessible. Furthermore, by being sold like any other category of consumer good, such as gum or snack food, this marketing approach downplays the potential risks associated with the consumption of drugs in general, be they pharmaceuticals, supplements, or natural health products. This situation is unlike the marketing of health

products in pharmacies, such as cough medicines or analgesics, which are usually confined to the back of the store (near the pharmacist's counter), and in a space that visually and spatially demarcates the fact that such products are distinct (in terms of regulated consumption and potential risks to health) from other consumer goods. Additionally, I find it troubling to see this collection of products being marketed in a generic fashion, with pills containing multivitamins made to appear equivalent to pills containing stimulants. It is questionable whether this constitutes a form a consumer deception, where the consumption of stimulant pills is 'normalized' and made to appear innocuous and widely acceptable, as is arguably the case with the consumption of multivitamins.

The targeted consumer group for these stimulants and supplements appears to be sexually active young adults that consume alcohol and are familiar with the bar and club scene. However, these products will likely be appealing to many other consumers, young and old, which should raise concerns as to how accessible these products are (or should be) to minors. It is important to note that these products do not display any prominent warnings and the fine print *within the inner leaflet* only recommends that these products not to be sold to children. Though these products are without a doubt inappropriate for children, they are displayed in a manner similar to that of candy, at the check-out counter with other cheap impulse-buy products such as gum, lip gloss or celebrity magazines. Thus, it appears doubtful that many children would be capable of differentiating these pills from other appealing items such as candy; a possibility made all the more startling by the fact that there are no *legislated* restrictions on selling these products to minors.

The availability and visibility of these pills points to a weakness with existing standards to protect vulnerable populations from harm, especially when compared to other heavily regulated items sold in corner stores. For one, the Québec government enforces strict regulations on the sale of alcohol and tobacco, where tobacco products in particular can no longer be in sight. Keeping cigarettes hidden from view is an attempt to 'de-normalize' their purchase and prevent vulnerable

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**STUDENT SUBMISSION:  
The Growing Popularity of 'Grey-Area' Drugs**

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populations, especially children, from being directly confronted with their attractive marketing and availability. In relation to the hard regulation of tobacco and alcohol, is it acceptable that other potentially harmful products like stimulant pills are visible and available to vulnerable populations, namely children? Indeed, I would go so far as to assert that current regulations are ethically unacceptable.

**NATURAL HEALTH PRODUCTS: A 'GREY-AREA'**

The assortment of pills sold at corner stores fall within a 'grey-area' of drug regulation. My choice of the term 'grey-area' is not denote an absence of regulation; indeed, most of these products are regulated by Health Canada under the category of *Natural Health Products* (NHP)<sup>1</sup>. Rather, I use this term to denote a 'fuzzy' and somewhat inconsistent regulatory structure. While a detailed overview of NHP regulation is beyond the scope of this commentary, certain conditions are worth noting. For one, unlike pharmaceuticals and over-the-counter medications, these products do not undergo rigorous testing for safety and clinical efficacy. This is why it is currently permissible to market dubiously effective 'aphrodisiacs' and 'stimulants that promote cardiovascular health' (Boost). Second, NHP is an umbrella category that includes products ranging from multivitamins, plant extracts, and the aforementioned 'fun' drugs of natural versions of Speed and Ecstasy. These drugs are regulated in terms of purity and for the absence of known toxic substances, yet these regulations are somewhat inconsistent. As an example, popular energy drinks contain the same active ingredients found in the aforementioned stimulant pill, *Boost*, yet they are regulated under the category of food<sup>2</sup>.

**THE PROBLEM OF MASS CONSUMPTION**

Due to the concerns outlined above, I believe strongly that such pills have no place among products being sold at convenience stores. Some may wonder why I have such a strong conviction, especially since similar products, like energy drinks, and now stimulant *candies* (for an example, chocolate flavoured 'Kickbutt amped energy balls', see [www.energyballz.com](http://www.energyballz.com)) are widely consumed in Canada. While the (over)-consumption of these products is problematic as well<sup>3</sup>, there is something particularly troubling with the broad sale of *pills*, which relates to my personal observations of the mass popularization of drugs that fall within this 'grey-area' of regulated control (not restricted like prescription medication, not illegal like illicit drugs).

For example, I often now see young adults openly consuming pills in the locker room before, and after, training sessions at the gym. These are not steroids.

Rather, they are readily accessible forms of stimulants and supplements sold online or at local pharmacies. Last summer while attending various outdoor festivals in Montréal, I was handed free samples of pills from the Purepillz company ([www.purepillz.ca](http://www.purepillz.ca)). These products were supposedly 'all natural' and legal variations of the illicit party drugs Speed (meth-amphetamine) and Ecstasy (MDMA). To my surprise, many people in the crowd showed no hesitation in consuming these products immediately upon receiving them. Recently, the Canadian media brought attention to the sale of placebos over the Internet that specifically target children as the end consumer<sup>4</sup>. These pills are a new tool to help parents deal with the daily aches and pains that accompany childhood in situations where a pat on the head and loving kiss simply will not suffice. Is the growing consumption of these 'grey-area' drugs getting out of control? I think so.

**THE ETHICS OF PILL-POPPING: DECEPTION, HARM—AS WELL AS UNJUST RESOURCE ALLOCATION?**

With the normalization of 'pill-popping' observed increasingly in my surroundings, I wonder if we are rapidly becoming a nation of drug addicts. I question the future implications this unprecedented pill culture will have on our society, especially in terms of harms to health. I question whether the public is well enough informed to realize that with the consumption of any drug there are certain risks to health, regardless of whether these products are in the form of candies, drinks, or pills, or the more mundane, coffee and alcohol. Are we witnessing a growing support for the misconceived idea that the solution to a variety of life's problems—be it weight loss, fatigue, the desire for muscle growth, more sexual desire, or improved concentration—can be resolved by drugs? Research indicates that this is a likely possibility.

For instance, Canada, in comparison to other OECD nations, shows significant problems in controlling spiralling costs associated with health care<sup>5</sup>, which primarily stems from our society's exorbitant consumption of prescription and over-the-counter drugs. Aside from undermining the sustainability of health care, our over-reliance on pill-popping as a health intervention may constitute a waste of scarce resources. The current overspending of resources on drugs may constitute an injustice since it does nothing to improve the health of millions of Canadians whose health would likely improve through non-drug related interventions. A recent report from the Canadian Institute for Health Information supports this criticism<sup>6</sup>, noting that the main illnesses that burden the health of our population will likely not be resolved by factors related to access to health care or medications. Rather, morbidity levels in our population are largely due to social-determinants and follow a socioeconomic gradient (health outcomes improve as one moves up the socioeconomic ladder).

Overall, it appears to me that our current over-reliance on drugs is undermining the sustainability of our health care system and is restricting resources that could be better spent on policies of social reform. The consumption of 'grey-area' drugs may play a role in this process. Definitely, their observed growing popularity suggests the inculcation of a pill-popping culture, and this may discourage future policy reforms that redirect resources towards addressing the social determinants of population health.

### SAY 'NO TO DRUGS' IN CORNER STORES

It is time for the Canadian bioethics community and government regulators to take a hard look at this 'grey-area' and reflect on the need for a greater degree of regulation of these products. The current broad availability and visibility of these products is particularly concerning. Indeed, drugs have no place in corner stores. Deeper reflection is needed as to whether these products are encouraging an unhealthy attitude towards mass

drug consumption and whether this phenomenon is compromising the sustainability of our public health care system. It is time for these 'grey-area' drugs to become popular in another sense: by being brought into the spotlight of a focussed debate on the potential harms innate within these widely consumed products.

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## Research Ethics and International Clinical Studies: Considerations in Latin America

For many individuals enrolling in clinical studies in developing countries, the only way to be protected from exploitative and unethical situations is through international guidelines, notably the Declaration of Helsinki and the Council for International Organization of Medical Sciences (CIOMS).

Since the beginning of 2000, there has been some disagreement over whether the US Food and Drug Administration (FDA) – the agency that regulates the US drug market and also wields considerable influence overseas – should continue to endorse the ethical requirements for international trials stipulated in the Declaration of Helsinki. Following the latest revision of the Declaration in October 2008, the FDA finally decided to abandon it and rely on the ethical requirements outlined in the International Conference on Harmonization's guidelines for Good Clinical Practice (GCP).<sup>1</sup>

Under the new FDA regulation, it would be possible to use placebos in control groups instead of the best available treatment; this is contrary to recommendations of both the Declaration of Helsinki and CIOMS. In a nutshell, as Kimmelman et al. explain, this would imply "less protection for participants" in developing nations since the aforementioned GCP is "silent" about ethical standards.<sup>1</sup>

This move by the FDA should raise serious concerns given that the number of clinical trials conducted in developing nations is growing rapidly. This growth was initially propelled by lower costs, availability of partici-

pants, and fewer regulations and monitoring,<sup>2</sup> and now by the possibility of using placebos.

In Latin America, for example, there is a substantial amount of biomedical research being conducted (clinical trials of phase I-IV), however most regional countries lack formal systems of ethical review. The only one with specific regulations and a public record of research is Brazil.<sup>3</sup> Thus, a large number of protocols are never evaluated, raising many concerns about the transparency of the projects, risks and benefits to research subjects, etc.

In particular, the vulnerability of the people in developing countries is a major challenge for their participation in research. Historically, the notion of vulnerability has been applied to children, prisoners and pregnant women, amongst others. But what happens in the case of persons facing difficulties in accessing needed basic health services in a timely fashion? This is the predicament in which millions of people in the developing world, thousands of them living in Latin America, find themselves. This vulnerability is further exacerbated by factors including high rates of poverty, social and political marginalization, difficulty in access to basic social services, and illiteracy (the latter understood not only in the sense of lack of schooling but also the lack of education in ethics matters).

All of these factors can be key determinants in a subject's decision whether or not to take part in biomedical research.

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**STUDENT SUBMISSION:**  
**Research Ethics and International Clinical Studies:**  
**Considerations in Latin America**

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For example, someone who needs medical treatment for which wait times are long, or which will be very costly, would probably be inclined to enrol in a study that offers constant medical care or the provision of medications that might not be acquired otherwise. In this situation, participants can mistakenly see a benefit for their health without distinguishing their participation in the clinical study,<sup>4</sup> or the fact that their might be no benefit at all.

Vulnerable people are more easily exploited, and so it should not be surprising that abuses are more common in those jurisdictions where regulatory systems and ethical review procedures are weaker or do not function properly, as is the case for many Latin American nations.

The absence of regulations and ethical evaluation remains a very troubling issue in Latin America. As noted by F. Luna, in general, the public is ignorant of ethical provisions included in biomedical research. With “informed consent” for example, participants are often unaware that this is used to protect their rights, and instead the consent form often becomes a “legal instrument” to protect researchers and institutions where the studies are conducted.<sup>5</sup> To make matters worse, a study by the Pan American Health Organization (PAHO) between 1999 and 2002 showed that in Latin American, there is in general a devaluation of ethical analysis; it is believed that foreign protocols do not need local review; and there is an overall lack of training in research ethics as well as a lack of regulations and deficient monitoring.<sup>6</sup> If the weakness of control mechanisms and the rarity with which unethical research is punished are also taken into

account, it is reasonable to affirm that research participants rest totally defenceless.<sup>5</sup>

International standards, notably the Declaration of Helsinki and CIOMS guidelines are widely accepted by the international scientific community. In most Latin American countries, these regulatory documents have a very important moral value and constitute (in the absence of local regulations) almost the only protection for participants in clinical trials. This is a very strong reason to promote their adherence. Governmental agencies as well as international observers, e.g., the WHO and the European Free Trade Association, should advocate for strengthening these guidelines, and work hard against moves (as in the U.S.) to undermine the protection of vulnerable research subjects in less developed jurisdictions.

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# Book Review:

## Just Health, Meeting Health Needs Fairly.

Norman Daniels. Cambridge University Press, 2008.

### JUST HEALTH FOR WHOM?

Resource allocation in healthcare distribution is one of the most challenging issues in health related policy-making. Norman Daniels, a philosopher interested in questions surrounding ethics in health distribution, significantly contributed to the discussion on ways to address fair resource allocation problems, initially focussing his attention on health distribution in the context of the US healthcare system with his book *Just Healthcare* (1985).<sup>1</sup> In his latest book *Just Health, Meeting Health Needs Fairly*, Daniels explores health distribution in various contexts, and shifts his focus to health

distribution as a result of public health policies, both at a national and international level (e.g., inequities in international health, variations in national public policy decisions). Being particularly inclined towards questions of justice and equity in health, Daniels draws attention to the need for the inclusion of ethical considerations in the context of public health policy-making, a field for which the integration of ethical considerations has not been prominent. This new book offers novel and useful tools for public health professionals and policy makers around the world wishing to elaborate policies that aim for better equity in population health.

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Similar to his previous works, Daniels' discussion of just health distribution here aims to answer one fundamental question: *What do we owe each other in terms of health possibilities?* Starting with the premise that health is an essential element that enables individuals to fully exploit their opportunities in life, he asks: *what is acceptable to require from each individual in order to promote and protect health in a population?* In order to provide a deeper outlook on this larger question, Daniels divides his investigation into three key questions: 1) *Is health of special moral importance?* 2) *When are health inequities unjust?* and 3) *How can we meet health needs fairly under resource constraints?*

Daniels argues that health is of special moral importance because it affects normal functioning of individuals, protecting individual opportunities and life-plans. It must thus be considered an essential element to the normal life-plans that individuals can expect to follow (or at least envisage) under normal conditions. Daniels argues that inequities, such as limited access to social determinants of health that undermine normal functioning of individuals, can be considered unjust. Social determinants of health being numerous, considerations on their potential impact on health distribution within and between populations should prevail in every public health decision.

A rights-based approach to resource allocation issues has been proposed as a means to address public health policy-making and distribution of social determinants of health. Daniels does not however follow this type of approach, and instead argues that human rights-based philosophies face significant challenges in being practically applied to priority-setting decisions. He argues that the reality of limited resources that predominates in health policy-making undermines the capacity of a human rights approach to respond fairly to the needs or demands of the various stakeholders implicated in the decision-making process, whether they be government officials or other individuals affected by health policy decisions. A human rights approach to policy making would, he argues, create strong opposition between tenants of preventive interventions and of priority to treatment interventions. Additionally, Daniels argues that a distributive justice approach (another approach proposed to resolve resource allocation issues) is no more suitable in the context of policy-making decisions, because there is no consensus on the principles that can guide decision-making processes in public health.

Daniels suggests that a possible alternative to these approaches is his theory of accountability for reasonableness, which can be applied to fairly address resource allocation issues and may allow adjustment to the various contexts in which decision-making about fair health distribution is required. The theory, developed in the 1990s in collaboration with James Sabin,<sup>2</sup> calls for the consideration of four major conditions in health policy-making: 1) transparency (publicity condition), 2) rationality

(relevance condition), 3) capacity to adjust to emerging differences in the distribution context (appeals condition), and 4) regulation of the proper application of the aforementioned conditions (enforcement condition).<sup>3</sup>

In *Just Health*, Daniels uses examples of emerging public health problems, such as global aging (understood as the aging of the world population) and intergenerational equity, consent to risk and health protection, or the tension between medical and moral professionalism (as exemplified by the HIV/AIDS epidemics), to explore the public health decision-making processes in various health related work environment decisions and life situations. Through these examples, he successfully brings the reader to a deeper understanding of the predominant problems in equity, justice and efficiency in health distribution and the complexity that accompanies their recognition. Daniels also elegantly demonstrates that accountability for reasonableness can be applied effectively to the elaboration and application of public health policies and of health policy-making in contexts of extremely limited resources (i.e., developing countries). However, even though he widens his scope of thought towards health distribution at a more global level, Daniels does not explore decision-making in health distribution at this level.

Discussions on health inequalities predominantly characterising the gap which separates the poor nations from the rich ones in the world are gaining increased attention in bioethics discussions. Authors such as Thomas Pogge, Tikki Pang, Peter Singer and Amartya Sen are amongst the many scholars shedding light on the striking lack of equity in the world concerning health distribution and opportunities within and between populations. Daniels's starting point on this issue focuses mainly on the social disparities that may account for the more general gap in population health. Thus, the causes of poor population health, according to him, reflect not only variations in national wealth, but also the weak social policies (lack of social networks) in many countries, which introduce inequities in access to social determinants of health such as education, food, housing, and work. Because of their impact on education possibilities or opportunities for work and life-plans in the populations, these policies diversify the avenues on which interventions can be deployed in order to reduce inequities in international and population health.

How then is it possible to tackle all the diverse facets of this important problem? Are international health inequalities unavoidable in our current society? If and when are international health inequalities unjust? Daniels does not provide answers to these emerging questions. What he does do, however, is open the discussion so that other ethics scholars or public health professionals can identify and better grapple with the complexities underlying the international population health gap. Global

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**STUDENT SUBMISSION:****Book Review: Just Health, Meeting Health Needs Fairly.**

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justice issues are amongst the most complicated current international challenges. Daniels expands the discussion to address important realities such as the brain drain of health personnel from poor nations to wealthier ones, international disagreements about intellectual property rights and the resulting access issues concerning medicinal drugs and health technologies. Rejecting theories of Human Rights, he proposes that tackling these issues requires ongoing philosophical work, and invites colleagues to reflect further on this topic.

*Just Health* will definitely be of interest for public health professionals and other stakeholders interested by public health related issues around the world. It should prove, as well, to provide a way to help solve the priority-setting problems encountered by government officials and other policy makers involved in public health policy-making in rich countries, but also in extremely limited resource contexts of the developing world. In so doing, *Just Health* offers a starting point for further in-depth reflection on

international health inequities, and the potential avenues available to address these challenges.

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Key words: Accountability for reasonableness, social justice, global justice, public health, developing world.

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# CALL FOR NOMINATIONS

## CANADIAN BIOETHICS SOCIETY 2009 NOMINATIONS FOR EXECUTIVE COMMITTEE

Nominations are invited for two positions on the CBS Executive Committee: (1) Member-at-Large, Central Region (Ontario) (2) Student-at-Large (Graduate). All CBS members are encouraged to participate in the nomination process by considering their own willingness to stand, and by recommending others whom they would like to see stand.

**POSITION DESCRIPTIONS**

**Members-at-Large, Central:** The position involves a two-year term that is renewable once. There are five Member-at-Large positions on the Executive. Members-at-Large provide representation for five regions of the country, participate in all Executive meetings, teleconferences and serve on sub-committees, as required.

**Student-at-Large (Graduate):** This position involves a two-year term that is renewable once. The Student Member-at-Large Graduate position on the Executive, providing representation for graduate student members of the Society. The Student Member-at-Large (Graduate) participates in all Executive meetings and teleconferences and serves on sub-committees, as required.

**PROCEDURE**

A valid nomination requires that the candidate submit a short (less than one-half page) biographical sketch, indicating interests and background, along with a letter of agreement to stand. Active members of CBS may vote for candidates to these positions at the Annual Business Meeting in June.

Candidates must be members of the Canadian Bioethics Society and nominations should be submitted by **May 31, 2009** to:

Dr. Paddy Rodney  
Chair, Nominating Committee  
c/o Lydia Riddell  
561 Rocky Ridge Bay NW, Calgary, AB T3G 4E7  
Phone: (403) 208-1619 [lmriddell@shaw.ca](mailto:lmriddell@shaw.ca)

## “Just Evidence?”



## "Quelle preuve pour une décision juste?"

June 11-14, 2009  
Hamilton, ON

The theme of this conference is justice in relation to global, local and clinical health. In particular, we will explore ethical issues around evidence-based knowledge, clinical care, health law, health policy and health related research. Conference sessions will be held at the Hamilton Convention Centre. A block of rooms have been reserved at the Sheraton Hotel, which is located directly across from the HCC.

### Speakers

- Maude Barlow:** National Chair of the Council of Canadians, and Senior Advisor on Water to the President of the United Nations General Assembly
- Jerome Wakefield:** Professor of Social Work, NYU, and Professor of Conceptual Foundations of Psychiatry, NYU School of Medicine
- Bernard Keating:** Past President of Canadian Bioethics Society, and Professor of Theology and Religious Science, University of Laval
- Rosemary Tong:** Distinguished Professor of Healthcare Ethics, and Director of the Centre for Applied and Professional Ethics, UNC Charlotte
- Susan Sherwin:** Professor of Philosophy, with cross appointments in Nursing, Medicine and Women's Studies, Dalhousie University



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For more information go to: <http://fhs.mcmaster.ca/bioethicsconference/>

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# GOOD HEALTH ~ HEALTH CARE: THE VALUES THAT LEAD US TO DIFFERENT DESTINATIONS

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## CONFERENCE REPORT

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All too often, the focus of ethics discussions in health care revolves around relatively parochial concerns. Yet some of the biggest issues we face when it comes to advancing the well-being of populations have to do with questions of much broader scope. So an important question that we struggle with at Fraser Health Ethics Services (FHES) is how to get issues of global justice onto the radar of local leaders.

Fraser Health is one of Canada's largest and fastest growing health regions. It serves a population of 1.5 million people, has a staff of over 22,000 employees and works with over 2,000 physicians. FHES began operations in the fall of 2005 with a mandate to meet the clinical and organizational ethics support needs of the region.

Since its inception, FHES has co-hosted an annual conference with another department in the region. This collaboration has proved an effective way of answering the above question.

On September 22, 2008 Fraser Health's departments of Health Promotion and Prevention and Ethics Services jointly sponsored a conference entitled Good Health ~ Health Care: The Values that Lead Us To Different Destinations.

Speakers included leading thinkers on the directions of health care from academia (Dr. James Dwyer of Upstate Medical University and Dr. Alice Dreger from the Medical School at Northwestern University), the media (Globe and Mail columnist André Picard), and global practice (Dr. Samantha Nutt of War Child Canada).

The conference aimed to broaden the scope of the conversations about challenging issues that take place at the leadership levels in the region. Invited guests included members of Fraser Health's Board and Executive Team, municipal leaders, leaders from the FH Directors Forum, leaders from the Health Promotion & Prevention portfolio, and members of the Fraser Health Ethics Network.

Specific topics covered at the event included:

- The value of health care in advancing the health of the population: Challenging the boundaries of health care in a global context
- Chasing Normal: The politics of science, medicine, and anatomy in the health of the population

- The Obesity Epidemic: genuine health concerns or a quest for beautification?
- Achieving health through social justice: An evolving framework for an interdependent world.
- Omigosh I've got Double X Syndrome! Sex and gender in health care
- Doctor shortage? No problem – let's import!
- An Apple or a Pill: When should the provision of health care begin?

The conference also provided an opportunity for graduates of the Fraser Health Introduction to Bioethics course to facilitate discussion using a systematic ethics process on cases in the contexts of HPV immunization, smoke free public spaces, influenza pandemic planning, and the relevance of lifestyle choices to access to services.

Overall, the conference was very well received. Evaluations were returned by 58% of participants. The majority of respondents found the content relevant and useful, significantly increasing their ability to identify and understand diverse values and perspectives. Many respondents felt it increased their ability to analyze ethical issues in a systematic manner and believed it improved their ability to dialogue about ethical issues with colleagues. Participant comments included *"One of the best plenary panels I've seen at any conference!"* and *"I loved the diversity of the topics — intense and eye-opening"*

For more information, please contact:

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# BIOETHICS: HOT OFF THE PRESS

As announced at the conference in St John's, the CBS is excited to present a reference list of recent bioethics articles in the newsletter. In this issue, publications from our membership are highlighted. Suggested citations or themes for future columns are welcomed. Please contact Stacey Page at [sapage@ucalgary.ca](mailto:sapage@ucalgary.ca) in this regard.

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# Canadian Bioethics Society

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