

Canadian Bioethics Society

NEWSLETTER

Volume 14, Number 2

January 2010



PRESIDENT'S LETTER

Al-Noor Nenshi Nathoo, 2009-2010

Dear CBS Member,

On behalf of the CBS Executive, I would like to take the opportunity to update the membership on a number of initiatives underway, and to solicit your feedback on the path forward.

- Copious thanks to the organizing team of our 2009 Annual Conference in Hamilton, led by Lisa Schwartz, for accomplishing the tremendous task of coordinating the conference on behalf of the CBS, and particularly of managing to attain a surplus of \$5,000 despite the economic climate. I'm not sure which of the two was the greater accomplishment, but based on glimpses into the incredible stresses involved in pulling off such an event with an almost exclusively volunteer team, neither seem much less than Herculean. As you may know, the surpluses generated from our annual conferences provide revenue for the Society to support special projects and advance important work, rendering it that much more significant.

- On that note, the CBS Executive is presently reviewing processes around annual conference organization to determine ways in which the Society and Executive may be able to pro-

vide greater support and continuity to its local organizing teams. One of the options under review is that of engaging the services of a conference administrator at the Executive level, who in essence would provide the human equivalent of seed money, but in the form of institutional memory and conference planning support to lighten the load (both emotional and physical!) for those charged with this heavy responsibility.

- At the Society's Annual General Meeting in Hamilton in June 2009, we welcomed Anne Heesters and Jennifer Bell to the CBS Executive as the Eastern and Graduate Student Member-At-Large Representatives respectively. Anne and Jennifer have already proven invaluable in helping the team think through and move forward on a number of the projects described here, including a number of new initiatives to enhance and strengthen student engagement and conference attendance, described further in the pages ahead.

- The 2010 CBS Annual Conference organizing team have been arduously preparing for our next meeting in Kelowna, B.C., June 9-12, 2010.

Thanks to Linda Sawchenko and the crew for a very promising start. The team was delighted with the response to the Call for Abstracts, with over 140 submissions received. The work now begins in earnest!

- We are happy to report that the organizing team for the 2011 CBS Annual Conference, to be held in St. John, New Brunswick, has also kicked into gear under the proactive leadership of Timothy Christie, scouting venues and addressing other long-lead items.

... continued on pg. 2

In this issue...

CBS Lifetime Achievement Award – Three Sayings 4

Student Reports: Welcome Back and Undergraduate Update 6

Student Submissions

- Eugenics: Discrimination or Discretion? 8
- Aribert Heim, Nazi Doctors and the Nuremberg Code 11

Canadian Palliative Sedation Therapy Guidelines – Moving Forward 12

6th International Conference on Clinical Ethics Consultation 15

Bioethics: Hot Off The Press 15



Conference info... cbskelowna2010.ca



Canadian Bioethics Society

NEWSLETTER

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

• The CBS-affiliated group affectionately known as PHEEP (Practicing Healthcare Ethicists: Exploring Professionalization) has been hard at work envisioning the next stage of the field's evolution in Canada. After a retreat held this fall, with support from the CBS, the group has identified a number of priority initiatives for the coming year, including the development of a Canadian-based response to the ASBH core competencies document, the development of professional standards for Canadian healthcare ethicists, and the launch of a survey of practicing healthcare ethicists in Canada regarding issues of professionalization. We look forward to seeing the results of this important survey. Congratulations to all PHEEP members for this truly exciting work and vision.

• As part of a process to clarify what it means to be an interest or working group affiliated with the CBS, a guidelines document has been developed to clarify structures and relationships between such entities and the larger CBS body. A related document, identifying a process for submission and review of applications to the CBS for funding of special projects when the CBS has the financial resources to be able to provide support, has also been developed. Both of these will be further refined in the coming weeks and posted on the CBS website for member comment.

• Following on the heels of hallway and tavern discussions taking place in Hamilton, a brainstorming meeting was held in Montreal in October 2009 amongst a number of Francophone members of the CBS, facilitated by Ghislaine Cleret de Langavant, Eastern/Quebec Region Member-at-Large, and attended by two other CBS Executive members, to deliberate on the notion of bilingualism in the CBS. The intent of the group was to explore whether the CBS as a bilingual organization is a reasonably attainable ideal in practice rather than only in policy, and if so, to identify specific, practical steps that the organization could consider to propel it closer to being inclusive in both name and essence. Although – as many members are more than acutely aware – this is not a new concern for the Society, the CBS Executive was unanimous that the issue was essential to maintain at the forefront, and central to the nature of the organization. Kudos and many thanks to all the members of this discussion group for their energy and commitment to an ideal which has proven, frankly, challenging for our Society (and more broadly of course, for our society). A number of recommendations were generated which have now received the support of the CBS Executive and will, pending feasibility, be implemented at future annual conferences and in our member communications. We would be grateful if you could take a moment to review these recommendations – posted on the CBS website – and to offer comments, additional suggestions or concerns.

• A CBS membership subgroup is revisiting the terms and benefits of CBS membership to determine how the Society might better meet the needs of its existing members and attract new ones to its fold to strengthen its base and more efficiently and effectively meet Society objectives. Comments from the membership on this, of course, would be most welcome and helpful.

• A CBS Website, Newsletter and Logo Design team has assumed the task of overhauling and updating the design and format of our existing Communications tools, with the primary aim of ensuring that they better serve the goals of greater collaboration amongst CBS members, enhanced support for academic and practice pursuits, and more comprehensive

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21st Canadian Bioethics Society Annual Conference
21e Conférence annuelle de la Société Canadienne de Bioéthique

information and access to resources for those in the field and the wider public. A draft structure for a redesigned website has been posted on the existing website for your review and comment. The team is also recruiting for a CBS Website Development volunteer, willing to contribute approximately 2-4 hours per week for 2-3 months, to assist in this initiative – please contact us if you are willing to be considered. Expertise in the field of knowledge transfer would be particularly appreciated, but not required.

- Based on feedback received from the membership at the annual conference in Hamilton, three finalists have been chosen as contenders for the CBS's new logo. We would appreciate it if you could cast your final vote for your preference, within the next few weeks, at <http://tinyurl.com/cbslogo>.

As we embark upon a new year, I would like to take this opportunity to acknowledge the incredible work of all those – conference organizers, affiliate group members, CBS Executive members, and many unnamed Society members

and volunteers – for their passion for bioethics and contributions to the field over the past year and beyond, many of which are undertaken quietly and without fanfare but are essential in 'building the house' of bioethics in Canada that Michael McDonald speaks eloquently of in this Lifetime Achievement Award address, cited herein.

Particularly relevant to the document you are reading, Stacey Page, your CBS Communications Officer, has demonstrated a supererogatory level of patience in pulling together this and numerous previous editions of this newsletter, despite the odds - our gratitude for her steady and unrelentingly respectful perseverance!

The members of the CBS Executive look forward to your feedback and inspiring ideas! Please write to us directly through our Corresponding Secretary Lydia Ridell at lmriddell@shaw.ca, or myself directly at nathoo@phen.ab.ca.

With warm wishes, Al-Noor Nenshi Nathoo.

THREE SAYINGS

By Michael McDonald

I was genuinely surprised when I received the note from Canadian Bioethics Society President Paddy Rodney that I was the recipient of the Lifetime Achievement Award for 2009. It was especially gratifying to receive the news from Paddy, who is a former student. I am most grateful to my colleagues in the CBS for this award. Thank you especially to those who put my name in for nomination. I have learned so much from all of you over the many years I have been associated with the CBS.

This occasion calls for appropriate remarks. But speaking as a philosopher, I cannot resist the inclination to offer a prolegomenon or a set of meta-remarks to set out my criteria for a speech that is appropriate on receipt of such an honour. I believe there are three criteria. First, the remarks must be relatively brief – we have been in sessions for nearly two full days and are reaching the super-saturated point. Second, the award is given following lunch so one's remarks should be digestible and not spoil the meal. Third and most challengingly, acceptance remarks must show some wit, but also display some seriousness.

An anecdote

So I begin with an anecdote. Years ago when I was in the Philosophy Department at the University of Waterloo, my then senior colleague and still close friend Rolf George told me a story about a conversation he had on a flight to his sabbatical in Germany. His seatmate asked what Rolf did. Rolf said that he was a philosopher. "Ah a philosopher", said the seatmate, "Tell me some of your sayings."

With his droll sense of humour, Rolf came back with the idea that each philosopher should develop some of his or her own sayings. Perhaps, Rolf suggested, faculty members could post their sayings on their office doors for potential students to contemplate.

Now this story may sound a bit strange to non-philosophers, but I find it most natural. I recall my first philosophy course which was in ancient philosophy at the University of Toronto in 1961-2. In that year-long course, we spent an entire term studying the very cryptic sayings of pre-Socratic philosophers who left only fragments of their work. As I recall, Thales talked about the composition of the universe claiming that everything is made of water. Heraclitus spoke about the nature of time and cryptically remarked that one can't step into the same river twice. I also have now rather dim memories that Parmenides worried about existence or the nature of being, but what remains fixed in my mind is that his followers, the Pythagoreans eschewed eating beans – thus linking being to non-bean. All this was

done before we were allowed to read Plato and Aristotle. As students, we were very grateful for finally having readings with premises and conclusions rather than cryptic sayings.

Nonetheless, sayings have their place, and one of these places is just such an occasion.

Sayings are not arguments. To one person, a particular saying may appear highly insightful, while to another it may seem like empty rhetoric. This is because sayings are context sensitive. So take into account this context – the receipt of an award at the CBS. I can then dispense with the standard philosophical qualification "ceteris paribus" or "other things being equal" and climb out on a rhetorical limb.

I have three sayings from my life experience in ethics and bioethics.

My first saying is that in ethics, what seems most obvious may be the most difficult and important to understand and act upon.

I found this in the work that I have done in research ethics particularly when I was a member and Deputy Chair of the Tri-Council Working Group on Ethics (TCWG) in the mid-1990's. I served on the Working Group with a number of distinguished academics including the late Doug Kinsella who served as President of the CBS. The Working Group produced the document that eventually became in 1998 the Tri-Council Policy Statement on the Ethical Conduct of Research Involving Humans. The tumultuous history of this paper is chronicled in a paper that I have just published in the *Health Law Review* (April 2009).

In this process, what shocked (and saddened) me was that most of the interventions and comments on our work were about the situation of researchers and how they might be disadvantaged by our formulation of research ethics norms. In the literally hundreds of pages of comments, we heard very little (outside the bioethics community) about the rights and interests of research participants, but we had numerous complaints and concerns about the rights and interests of researchers. I came to realize that the voices of research subjects were seldom, if ever, heard; while the voices of the research community and sponsors dominated the correspondence and protection processes.



As we conversed with the research community, I realized that researchers had made assumptions about the burden of proof. The common view was that it was the responsibility of the TCWG and critics of current practices to show that something was wrong with the then current arrangements for research governance. It seemed obvious to me that the burden of proof lay on the research community to show that research subjects were effectively protected. This insight led to the work that I led on our report to the Law Commission of Canada in 2000. In that report we noted that while research ethics abounds with norms and procedures there is really no attempt to garner evidence of effectiveness of those norms and processes.

In the work that I have done on research ethics since that time, I have come to realize that on paper what happens to research participants is supposed to be central to research ethics norms. However, almost no one really systematically tracks the experiences of research subjects. This simple and obvious insight led to our current research project on the experiences of research subjects.

Finally, I have noted that while research ethics is profoundly shaped by its history, we as Canadians study and invoke the US history of human research protection but typically ignore our own history and situation as Canadians.

My point in all this is that in puzzling through the often controversial process we had in the lead up to the Tri-Council Policy Statement, I was led to think very hard about how we in Canada govern human research protection. With colleagues I have launched multiple research projects, including research into governance and into the experiences of research participants, to address what seems like the most obvious and yet most neglected questions. It has led me to argue in favour of an evidence-based system of Canadian human research protection in both academic and policy forums.

Finally, I want to say that research ethics is a crucial part of bioethics. It is essential for those who work in this area make it a prominent part of each CBS meeting. It is also essential that we engage in serious scholarship on the history of the Canadian experience in human research protection.

My second saying is that before there can be occupants, someone has to build the house.

Let me offer some examples of building the house of bioethics from my career. One was the creation of the applied ethics strategic research theme at SSHRC that funded work in bioethics and other areas of applied ethics in the late 1980s and 1990s. This was only possible through a concerted effort on the part of several bioethicists including Sue Sherwin, and Abby Ann Lynch as well as my research assistant at that time Daryl Pullman. A second is the work that many of us did to ensure that when CIHR was created ethics was a cornerstone of its foundation that is even a part of its legislated mandate. Another was in the creation of the highly interdisciplinary W. Maurice Young Centre for

Applied Ethics at the University of British Columbia. I was also privileged to be part of the movement that brought about the integration of social sciences into bioethics. Finally I would mention the CIHR ethics training program that our Centre has had with Dalhousie University.

My point here is that many of the things that we now take for granted were not always there. Someone has to build the house before there is a roof over our heads. We need institution builders. This requires entrepreneurship and creative partnership working for the common good. The items that I mention were not things that I could have done on my own. They required a shared effort and putting aside personal ambitions and partisan agendas.

My third saying is to be passionate and thoughtful, but above all be compassionate.

What we do in bioethics should ultimately matter to patients, families, research participants, our community and our world. We should be making a positive difference for their lives as well as our own. Bioethics requires thoughtfulness and insight. The issues we engage with are intellectually and practically difficult.

We will encounter resistance because what we say will threaten the comfortable and powerful. As bioethicists we need to have the courage of our convictions and not only speak truth to power but demand that the powerful be truthful. That is not easy and is certainly not, in my experience, without personal cost. In difficult moments it is crucial to have supportive colleagues. I have been blessed with these particularly in the Centre, on the Tri-Council Working Group, the CIHR Standing Committee on Ethics and in other circumstances.

But above all I urge you to be compassionate. Two years ago I was shocked to learn that I had a serious cardiac problem. I was no longer the ethics consultant and teacher walking into the hospital, but a patient with an ill fitting gown and a fear-filled mind. My family physician said to me that perhaps I would learn something from this experience that would be useful in my work as a bioethicist. She was right about this. I did learn something from family, friends and caregivers as well as fellow cardiac patients. What I learned is the importance of compassion and caring.

As bioethicists we have the intellectual platform and practical opportunities to inspire and nurture a culture of compassion in health care and health research. I urge you to continue to take such occasions with the passion that they deserve.

So these are my sayings.

I trust that I have not over-burdened the occasion or your digestion. I hope that these sayings will either have resonated with you or, if not, have pushed you into useful indignation. A good feature of sayings is that they are not really arguments but hints at ways of life. They require some sharing of life experience and that is what I have tried to do on this occasion. Finally thank you again for this wonderful award.

STUDENT REPORTS

WELCOME BACK

By Jennifer Bell

and

UNDERGRADUATE UPDATE

By Gina Freedman



Greetings and welcome back for the 2009-2010 school year! I hope you had a wonderful summer!

I would like to introduce myself to you as the new graduate Student Representative for the CBS/SCB. I am honoured to take over this position from Meredith Schwartz who did an exceptional job of increasing the student programs,

awards, and funding to support conference attendance for the CBS/SCB annual meeting. Meredith was also able to streamline the student abstract submission and review process as well as increase student awareness of the CBS/SCB through novel avenues such as the social networking website, Facebook. Thanks, Meredith, for all your hard work and devotion to addressing issues that are important to CBS/SCB students.

The city and conference committee warmly welcomed us to the 20th Canadian Bioethics Society Conference, *Just Evidence?*, in Hamilton, Ontario! Sixty students attended this year's conference, and many students presented papers or posters. This year there were a number of continuing student programs at the conference. These included: the student abstract competition, the student meet and greet, the student mentor breakfast and travel bursary programs. During my term as the student representative, I plan to continue these excellent student programs and find new ways to make the Canadian Bioethics Society Conference more accessible to students. I am looking for suggestions for further student fundraising programs, and suggestions for future bioethicists you would like to eat breakfast with as part of the student mentor breakfast program. If you have ideas please send me an email, or if you are a bioethicist who would be interested in taking part in this event at future conferences, please send me an email.

The student abstract competition: Fifty abstracts were submitted to the abstract competition this year from which seven winners were selected.

The student travel bursary: The travel bursary is funded by the CBS/SBC and student fundraising efforts, and

helps with the cost of attending the annual conference. Congratulations to this year's student travel bursary award winners:

Julie Bull, Dalhousie University

Chris Chalmers, Dalhousie University

Samantha Copeland, Dalhousie University

Constance Deslauriers, Institut de recherche cliniques de Montréal

Yanick Farmer, Université de Montréal

Billie Hilborn, University of Toronto

Ghislaine Mathieu, Institut de recherche cliniques de Montréal

Catherine Rodrigue, Institut de recherche cliniques de Montréal

News about the 2010 CBS/SCB student abstract and bursary competitions: In order to streamline the application process for the student abstract competition and the student travel bursary, there is a new email account specifically for submitting to the student programs. When the call is opened, please send your abstracts and bursary applications to <studentscbs@gmail.com> for the 2010 conference to be held in Kelowna, British Columbia.

In order to recognize the winners of the student abstract competition and the student travel bursary, the prizes for these programs will be awarded at the annual CBS/SCB Student Business meeting in 2010. More information on these programs will be forthcoming in the next issue of the *CBS/SCB Newsletter*.

OPPORTUNITIES FOR STUDENTS!

The CBS/SCB has many opportunities for students to become involved! The following open positions will allow you to network with colleagues and students in bioethics, provide you with valuable practical experience, and look good on your CV. Please email Jennifer or Gina (unless otherwise indicated) if you are interested!

Chair of Student Conference Committee: The Kelowna conference committee is looking for an interested and engaged local student to help plan the student conference programs for the upcoming 2010 CBS/SCB

annual conference in Kelowna, British Columbia. If you are interested in this position please contact the Chair of the Conference Committee, Linda Sawchenko, directly at: Linda.Sawchenko@interiorhealth.ca

Chair of Student Abstract Committee: We are looking for a responsible student to host the 2010 Student Abstract competition. Roles and responsibilities involve managing the abstract review process in consultation with Jennifer and Gina. Email us for more information or if you are interested.

Francophone Ambassador: This is a newly created position that we hope will increase francophone student involvement and representation in the CBS/SCB. The Ambassador will be engaged in the roles and responsibilities of a University Rep (details below) with the additional responsibility of consulting with Jennifer and Gina on francophone ideas and concerns. If you are already a University Rep in Québec we encourage you to consider this position as well. Francophone students who aren't yet University Reps, but are interested in becoming more involved with the CBS/SCB, are also encouraged to contact us.

University Reps: The university representative program continues to grow! Are you interested in becoming a member of the team? We are especially looking for University Reps from Saskatchewan, Manitoba, New Brunswick, PEI, and the Northern Territories, as these regions are currently underrepresented. The roles and responsibilities of the University Rep are simple, but important:

1. BE PRESENT – attend bioethics club meetings and visit bioethics classes at least once a year to tell them about Student CBS/SCB; get to know the bioethics profs as well; *if you are comfortable, give out your email address when you visit*
2. BE A HUB – allow me and others to contact you, and contact me and others to keep CBS/SCB informed on important issues (scholarships, new developments, growing programs, new centres)
3. MAKE OTHERS AWARE – advertise for the annual

conference (post posters); *if you are comfortable, write down your email address at the bottom of the flyer*

If this job sounds interesting to you, please send me an email to let me know that you would like to be part of the University Representatives. A big thank you to the following new local university reps who volunteered at the 2009 CBS/SCB Student Business meeting in Hamilton:

Michelle Cleghorn, University of Toronto

Spencer Hey, University of Western Ontario

Alexandra Mogyoros, University of Guelph

Mazen Zehairi, McMaster University

Contributions to the CBS/SCB Website: The CBS/SCB Executive is looking for students who are interested in contributing content to the CBS/SCB website. No previous web experience is required.

Contributions to the CBS/SCB Newsletter: If you have a paper you would like to submit for publication, we are interested in hearing from you! (please contact Stacey Page, sapage@ucalgary.ca)

Once again, I would like to thank you for giving me the opportunity to represent the students of the Canadian Bioethics Society. Throughout my term, I will continue to improve the visibility of the CBS/SCB student programs by communicating through the CBS/SCB website, a new CBS/SCB student listserv and site on facebook.com. I hope that these means of communication will increase students' awareness of the Canadian Bioethics Society and will continue to build the ever-growing student body of the CBS/SCB. Please feel free to send me an email with any comments, questions or suggestions at any time. I am looking forward to seeing you at the 21st Canadian Bioethics Society Conference, which will be held in Kelowna, British Columbia in 2010!

Jennifer Bell is currently completing her Doctorate in Interdisciplinary Studies specializing in Bioethics at the University of British Columbia.

<jahbell@interchange.ubc.ca>

Undergraduate Update Fall 2009

The Hamilton conference was a great success; we welcomed a new graduate rep, Jennifer Bell, and were proud to announce the establishment of new student awards and the enrichment of current student bursaries. The student awards approved at the Hamilton conference include the creation of two new undergraduate abstract awards. These awards, in the amount of \$900 each, will be presented at next year's conference and are a fabulous new opportunity for students at the undergraduate level. The amount awarded to student travel bursary winners

next year will also be increased to \$300 each. I highly encourage undergrads to apply for either of these awards or bursaries.

At this year's conference, I met lots of undergraduate students and got a lot of good feedback about what *you* would like to know about working and learning in the field of bioethics, as well as the direction that *you* would like to see the CBS student program moving in. Jennifer and I are starting to work towards next year's conference in

... continued on pg. 8

Kelowna, and your feedback will be of great help as we plan the student portion of the conference. Hope to see you in Kelowna!

At next year's conference my term as the undergraduate representative for the Canadian Bioethics Society comes to an end. For undergraduate students interested in becoming involved in bioethics and the Canadian Bioethics Society the undergraduate representative position is a great way to gain experience and establish contacts in the bioethics community. More information about applying for this position will be available in the next newsletter. If you'd like to know more about the position, the responsibilities and benefits, give me an email and I'll be happy to share.

As well as the upcoming vacancy in the undergrad rep position there are a great many opportunities within the Canadian Bioethics Society for undergrad students. CBS

is in the process of launching a new website and needs content providers. Getting involved in the creation of the new website will allow you to be a part of the development of CBS's public image and will help you get the inside scoop on what's happening in bioethics in Canada. The opportunity to be a local rep for your university is also open to undergraduate students. Being a local rep is a great way to get involved in both your local university and in the wider bioethics community.

If you are interested in any of these positions please do not hesitate to let Jennifer or I know, we look forward to hearing from you! As always I invite any undergraduate student to contact me with questions or any ideas of how CBS can better address the needs of undergraduate students interested in bioethics.

Gina Freeman recently completed a bachelor's degree in Biology at the University of Calgary. She begins her graduate studies in Bioethics at McGill University this fall.
<freemang@telus.net>

STUDENT SUBMISSIONS

The CBS Newsletter is pleased to present two 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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Eugenics: Discrimination or Discretion?

Introduction

Developments of new technologies in the medical field now allow us to determine the health of our children in the fetal or even pre-implantation stages. This means that embryos and fetuses can be tested for physical or mental disabilities; parents or medical personal have the opportunity to select or reject, and thereby determining whether to continue or even begin the pregnancy process. This development leads us to question the rightness or wrongness of exercising this ability and to ponder the message it sends to those who already exist with such disabilities. It is this author's opinion that it *is* discriminatory to choose to abort a fetus based on its possible disabilities but, unlike the concept which is connoted by the term *discriminatory*, the action is benevolent in nature. First, we may explain the fallacy which arises in describing an action as "discriminatory" as well as "eugenics" and correlate the two terms to distinguish their impact on morality once defined. Secondly, the term *disability* must be defined to determine what ailments may be considered under its purview, thereby providing us with a basis on which to

judge its desirability as an attribute. Thirdly, I intend to discuss these two terms in relation to (fit the two of these in with) current Canadian guidelines on abortion to show that the choice of genetic abortion or pre-implantation testing ought not to be associate with disapproval but rather is the appropriate choice to make where possible.

Discrimination and Eugenics Defined

For the purpose of our discussion it would appear appropriate that *discrimination* be defined. Discrimination possesses different definitions. According to Webster's Dictionary the term *discriminatory* can mean "to make a difference in treatment or favor on a basis other than individual merit". This paper assumes that this is the intended meaning of discriminatory, by virtue of the wording of the essay question proposed. Webster's also defines Discriminatory as "1a: to mark or perceive the distinguishing or peculiar features of; b: distinguish, differentiate; 2 to distinguish by discerning or exposing differences; especially: to distinguish from another like object." Out of particular context, these definitions appear to be morally ambivalent. It is evident in the essay

question that the use of the word “against” is associating a negative connotation with the word discrimination. The question that follows is: Need this negative implication be inferred by the eugenic message? For the moment we can move forward preserving the possibility that, aside from disapproval, discrimination can also infer neutral or even positive implications.

Webster’s dictionary defines *eugenics* as “a science that deals with the improvement (as by control of human mating) of hereditary qualities of a race or breed”. As Dan Brock suggests, in *From Chance to Choice*, “when particular uses of genetic technology and science are branded as ‘eugenic,’ the label points us to an evil that eugenics represents” (28). Brock points out how the origin of eugenics was centered on racism, classism and, most prominently, intellectualism (29-40). An important issue when considering this historical perspective is the association that in the past placed on these, now negative, “isms”. The use of eugenics became associated with bias and bigotry, an unnecessary social connotation which was fused with the term due to its unfortunately socially unacceptable origins. This paper will consider the use of eugenics as ‘selective breeding’ and will focus on the scientific aspect of selection as opposed to personal choice aspect. It is difficult, and an altogether separate issue, to argue regarding the prejudice of selective breeding based on a ‘personal preference’ perspective of partnership. The scientific aspect of eugenics refers to any intervention beyond the couple procreating which will determine attributes and characteristics of the child.

What Constitutes a Disability?

The term, disability, according to Webster’s literally means the “lack of legal qualification to do something” or “a disqualification, restriction, or disadvantage”. As it is defined by the Ontario Human Rights Commission disability is “any degree of physical disability or disfigurement; learning disability or any dysfunction in the ability to understand or use symbols or speech; intellectual impairment; and mental disorder” (1). These definitions make it clear that the notions of disability are socially created. Assessing what constitutes a ‘disability’ and its impact on societal notions of the term are important in determining what beliefs may accurately fall under the scope of discrimination.

It is this author’s proposal that not all attributes which are currently defined as disabilities are negative; therefore, for this paper, the term *inability* will be applied to such attributes which ought not to have negative connotation. To consider a *disability* as a negative, the corresponding ability must first be considered a positive attribute of being a person. The notion of the majority’s opinion being our determinant for defining disabilities seems appropriate, as disabilities are deemed as such due to the majority’s ability to perform the task in question.

It is important to discuss this point further, as there is a hierarchy of ability for most actions. Those in the middle or higher position of this hierarchy do not fall under the category of “disabled” as defined above; this fact furthers the notion that what denotes “disabled” must stem from creation of expectation by society. For instance, I am not afforded special rights as a disabled person as a result of my inability to perform complex mathematical calculations in my head, as it is not expected that I ought to be able to, since most others can not perform this task either. It would follow then that the concept of ability is derived from one’s proximity to the mean, or norm, of society. Since this ‘majority’ is not exact in terms of ability, with some exceeding and some lacking regarding our ‘norm’, it ensues that the area of the norm has a range with a lower and upper echelon defining its borders which, similar to disability, is socially created. It does not seem necessary to argue for those who surpass the norm in facility. What of those who fall below our socially constructed notion of normal though?

Quality of Life

Since our idea of disability is socially constructed in relation to our socially constructed concept of what constitutes normal, does it not necessarily follow that what is to be considered in the realm of disability ought to be socially constructed as well? There must then be a manner to determine what constitutes a disability. I will argue that *quality of life* is the method by which we determine what comprises a disability. Quality of life refers to the subjective interpretation of “the presence or absence of pain and suffering, and of the cognitive, emotional, and physical ability to have opportunities for achieving a decent minimum level of well-being” (Glannon, 61). It becomes difficult, yet important, to determine the *quality of life* for such individuals. If there is little or nothing for an individual to live for, then one is said to have a low quality of life; it does not follow though that simply because one’s abilities do not fall under the category of “normal”, his or her quality of life will be low and therefore the disability justifies abortion. It must then be determined which of these, if any, ought to fall under this category. The problem which arises is that quality of life is a socially *subjective* concept in itself. The only foreseeable way by which to avoid this problem of subjectivity is determining by *reason* what may or may not fall into the category of disability. Unfortunately, even through reason, we are left with a grey area, a subjective idea of disability which may fall subject to discriminatory acts. It seems reasonable that first we eliminate concerns of quality of life which may *not* fall under the category of disability, thus allowing us to narrow down the range which, arguing by way of socially constructed truths, may ascribe some rational to questioning the morality of genetic abortion or pre-implantation diagnosis.

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STUDENT SUBMISSION:

Eugenics: Discrimination or Discretion?

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The first, easiest, and I believe most important to eliminate, is the category of *individually determined disability* (IDD). This term will be used to describe the category of “disabilities” which are not predictable as such and can be attributable to an individual bias or illogical reasoning. In these cases there is no generally accepted notion of superiority or inferiority attached to the “undesirable” human attributes; therefore they may not be considered legitimate disabilities. An example of this is the gender of a child. Although there are situations in which one sex may benefit over another, this may not be considered a disability as quality of life may not be reasonable assumed to be better for one sex over another. Examples which refute this claim, such as sexism, are generally recognized shortcomings of society which hold no claim to reasonably infer that a child may be better off with the attributes of one sex over another.

In this essay, the extent of these illegitimate claims of disability will not be touched on, nor will the exact line of what constitutes disability be defined. The focus is on creating a generally accepted definition which embraces a socially created reality which legitimizes the definition of “disability”. The intent of this is to show that the very social reality which created the term *disability* is what determines quality of life; therefore, one can reasonably use a socially created determinate as a morally sound basis for genetic abortions or pre-implantation diagnosis.

With the area of IDD eliminated as unjust, we may consider those attributes of an individual which may fall outside of its purview. This category, which may justifiably be describe to contain aspects of disability, ranges anywhere from blindness and deafness to Down’s syndrome and severe learning disabilities. Although there remains a grey area which will not be discussed in this paper, for reasons which I hope will be more evident shortly, the above mentioned traits will undoubtedly affect quality of life, as it is defined by the majority, in a negative manner. I will assume for the purpose of this paper that it is generally accepted that those attributes which society considers disabilities are undesirable attributes and carry with them a negative association. At this point it is not necessary to separate between IDD or true ‘disabilities’. The point is actually enhanced if one considers IDD’s for this purpose. It does not follow that a negative association with one receiving an undesirable attribute is analogous with a negative opinion of those living with such an attribute. If I do not wish to have Down’s syndrome, nor do I wish it upon my children, it does not mean that I hold any ill will toward persons living with Down’s syndrome. To place it in terms which hold less emotional grip, if I do not wish to have brown hair, nor do I care for my children to have it, it does not necessarily follow that I negatively *discriminate* against living persons

with brown hair. Discrimination may simply mean, as defined previously, *to observe differences in people*; it is not necessary negative to discriminate and it does not follow that a person’s desires for future possibilities are required to affect his or her positive beliefs of present actualities. While this argument is tied into the relevance of abortion, it is important to keep in mind two questions: First, if given the opportunity to wake up tomorrow with a permanent disability or as you are at the present, which would you choose? Secondly, do you hold animosity towards any living disabled persons as a result of their condition?

Abortions Place in Discrimination

The focus of this paper is disability and discrimination, not abortion. For considerations of length and clarity, the morality of the act of abortion will not be examined at this time. However, current Canadian laws and regulations which guide abortion will be used to discern what effect, if any, the act of aborting ought to have on the relation of disability and discrimination. In 1982, Canada enacted the Charter of Rights and Freedoms, section 7 of which states, “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” As a result, the Canadian abortion laws in place at that time were deemed unconstitutional. Chief Justice Brian Dickson writes, “Forcing a woman, by threat of criminal sanction, to carry a fetus to term unless she meets certain criteria unrelated to her own priorities and aspirations, is a profound interference with a woman’s body and thus a violation of her security of the person.” Canada thereby became one of a small number of countries without a law restricting abortion” (CBC). Although there have been numerous important contentions over the ruling, to date Dickson’s legal precedent guides Canada’s abortion laws today. Pence points out that the implications of this is that a fetus does not possess the rights and protection afforded to a ‘person’ (175-176) Although there remains in place criminal law in Canada (Criminal Code, sec. 287) which does touch on aspects of abortion, the motive behind such laws is directed at protecting the mother of the fetus, not the fetus itself. This is the extent to which abortion will be considered; further analyzing the issue will bring to light moral questions which do not pertain to the question at hand.

What then is the relevance of abortion to disability and discrimination? Quite simply: It plays no role. Asking the question, “Do you wish to abort your disabled child?” is no different from asking, as a topic unrelated to an existing pregnancy, “Would you prefer to have a disabled child or not?” Although this appears to dismiss the moral implications which are a highly controversial topic, it does not. The notion of socially created truths hits an impasse regarding the morality of abortion, with no clearly defined truths for either the pro-life or the pro-choice sides. The decision of the law to default to pro-choice is a logical side to take. The importance of this is that, in a moral

dilemma where neither side is clearly the winner, the choice is in the individual's hands, thereby placing no more worth on the child than the mother does. In so doing we warrant the abortion of a child with a disability without naturally assuming discrimination of those living with a disability. The reason this allows discrimination to be eliminated as necessary inference is the individualistic application of an accepted notion of choice. If one does not wish to for their children to have a disability, and making such a decision does not impede on *any* other individuals rights, then there is no harm in making such a choice.

Conclusion

The terms *disability, discrimination, abortion and eugenics* all have the ability to carry negative implications. By defining these terms and separating circumstances in which the negative connotation is justified, from those in which it indicates prejudice, society has the ability to ascertain which decisions ought to fall under the purview of the individual versus those which ought to be governed by a higher body. The choices individuals make regarding disability, for themselves or their children, do not necessarily correlate to bigotry towards disabled persons. Instead, the decision simply represents what constitutes

a suitable quality of life *for the individual* in question. Personal preference does not necessarily impede the rights or quality of life of disabled persons; therefore the choice to abort due to disability ought to be the decision of the parents with no external influence.

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Aribert Heim, Nazi Doctors and the Nuremberg Code

The reported death of Aribert Heim is an opportunity to take another look at a major episode in the evolution of the ethics of biomedical research.

According to a story in the August 14, 2009, issue of the *Daily Telegraph*, the German police confirmed that a briefcase and documents discovered in Cairo had belonged to Aribert Heim, the former Nazi known as "Dr. Death" and the "Butcher of Mauthausen." This news has reignited the debate about the presumed death of one of the most-wanted Nazi war criminals. As the spotlight comes to bear once again on the history of Nazi medicine, now may be a good time to re-examine this dark chapter of biomedical research and review what we have learned from it.

Last February a joint investigation by German television network ZDF and the *New York Times* revealed that Aribert Heim had died in 1992. ZDF and the *NYT* reported that the Nazi war criminal, one of the world's most wanted, had apparently died of intestinal cancer in Egypt, where he had been living in hiding for close to 20 years. The report confirmed

the version of the German police, but was treated with suspicion by the Simon Wiesenthal Center, an organization devoted to tracking down Nazi war criminals. In May the German police took a different view when they told the German news magazine *Der Spiegel* that, in their analysis, the documents did not constitute evidence of Heim's death and that the investigation was ongoing. On

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August 14, however, the *Daily Telegraph* published a story saying the police had declared that analysis of the documents established beyond any doubt that they had belonged to Heim. Moreover, analysis of dust samples from the briefcase showed that it had been in

Egypt for several years. Although this information did not prove Heim was dead, as ZDF and the *NYT* noted, it did provide further evidence that he had lived in Egypt. The only way to confirm the death would be to find and identify the corpse.

... continued on pg. 12

STUDENT SUBMISSION:**Aribert Heim, Nazi Doctors and the Nuremberg Code**

– continued from page 11 ...

Dr. Heim committed atrocities on hundreds of prisoners held at the Mauthausen concentration camp in Austria during the Second World War. After studying medicine at the University of Vienna, he joined Heinrich Himmler's SS in 1938. In 1941 he became head physician at Mauthausen, where he performed surgery without anaesthesia, removed organs from living subjects and injected various poisonous substances into his victims' hearts. After the war, he was imprisoned for having belonged to the Waffen SS, but his criminal medical practices were not revealed. He was released in 1947 and practised medicine in southern Germany. At the trial of another ex-Nazi, a witness identified Heim as "Dr. Death." In 1962 he fled and went into hiding just as the German police were about to arrest him.

Heim was far from the only Nazi doctor who carried out cruel biomedical experiments. One of the postwar Nuremberg trials dealt with Nazi doctors. At the so-called "Doctors' Trial," 20 physicians were charged with committing war crimes and conducting criminal experiments. Ethical principles were drawn up in the wake of the trial and now constitute what has become known as the Nuremberg Code. Among these principles are voluntary, informed consent of subjects, freedom of choice of subjects to end their participation in an experiment, scientific rigour and relevance, and minimization of risks to subjects. The principles are fundamental to contemporary regulations.

Though accepted by the scientific community, the principles have not always been followed. In 1966 Henry Beecher, a physician and professor at Harvard, published a paper in the *New England Journal of Medicine* in which he pointed the finger at 22 research projects that he

deemed to be unethical: they involved injecting cancer cells into elderly, senile patients; depriving syphilis patients in a clinical trial control group of penicillin and allowing their condition to worsen; and deliberately inoculating young psychiatric patients with the hepatitis B virus while developing a vaccine. Twenty years after Nuremberg, research subjects' rights were still being ignored. Beecher's paper led to the development of better guidelines and stricter control over research.

Now, despite undeniable progress, some observers fear new abuses. The pharmaceutical industry, for instance, in an effort to reduce production costs, has increasingly been conducting clinical trials in developing countries. Ethicists are worried about compliance with safety standards and the quality of the consent being given by particularly vulnerable subjects. So even today, when the ethical framework for biomedical research prevents abuses of the kind perpetrated by Dr. Aribert Heim and his colleagues, there are still good reasons to remain vigilant.

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CANADIAN PALLIATIVE SEDATION THERAPY GUIDELINES – MOVING FORWARD

A small working group was formed in the Spring of 2008 to look at the status of palliative sedation guidelines in Canada and to move forward with the establishment of a consensus-based set of clinical guidelines to provide clarity on the somewhat controversial ethical and medical issues related to this practice. Currently the working group consist of Dr Larry Librach, Dr Victor Cellarius from the Temmy Latner Centre for Palliative Care in Toronto, Dr Mervyn Dean from Corner Brook, Newfoundland & Labrador, Dr Doreen Oneschuk from Edmonton, Alberta, and Blair Henry, Ethicist at Sunnybrook Health Sciences Centre in Toronto.

Palliative sedation therapy (PST) has received both supportive and critical attention over the past two decades. Most recently, one needs only to refer to recent reports, posted in the U.K. Telegraph, outlining concerns being expressed by the adoption of the Liverpool Care Pathway (LCP) within the National Health Service in Britain,¹ to understand that sedation at the end of life continues to be a deeply contentious issue. The term "terminal sedation" first appeared in the literature in the 1990's in Enck's review of two articles concerning symptom control at the end of life². Since then many definitions have been put forward for sedation used in

palliative practice, but at the core they share the ideas that PST is:

- 1) The use of (a) pharmacological agent(s) to induce reduced consciousness;
- 2) Reserved for treatment of truly distressing and refractory symptoms;
- 3) Only considered in a patient that has been diagnosed with terminal illness;
- 4) Usually considered only in patients in whom death is imminent.

PST appeared in the literature as an already existing practice and very little is known about its development prior to this appearance. The literature indicates that there are large differences between centers and countries with regard to: the frequency that PST is provided, the indications for it, and the manner in which it is administered. Some countries have produced national guidelines^{3,4}, but in Canada any guidelines have been regional^{5,6}, or specific to defined areas of the hospital⁷.

The proposed project, undertaken by our working group, will attempt to formulate national guidelines for the use of PST in Canada. It will describe the current state of PST in palliative practice in Canada, and it will prescribe practice based on previous literature, previous guidelines, survey data, and expert opinion. In this way, the proposed project seeks to create a consensus guideline on PST use in Canada.

An initial question regarding PST concerns what sort of treatment PST is understood to be. Even the term to use for the procedure varied considerably: “sedation therapy”; “terminal sedation”; “sedation for intractable distress in the imminently dying”; “end-of-life sedation”, “total sedation”; and “palliative sedation” among others were noted during our literature search on this topic. Our working group has agreed to adopt a recent international consensus paper recommending the term “Palliative sedation therapy”⁸. The term PST reflects the fact that sedation correctly practiced is symptom management, and not euthanasia⁹. Inappropriate use of PST has led to the term “slow euthanasia” being used by some authors^{10,11}.

The practice of PST involves many ethical issues which will need to be addressed in the consensus guideline. A salient example of one such ethical issue involves the provision of nutrition and hydration (N&H) as an adjunctive treatment with PST. The subject of N&H is always an emotional one for caregivers, and its lack of provision for sedated patients has been used to argue that PST is a form of euthanasia. Even in the non-sedated patient at end of life there are no clear guidelines regarding the provision, or not, of N&H¹². It is argued that PST and N&H are, in fact, separate issues the merits of each of which must be considered separately^{13,14}.

PST has considerable ethical ramifications for healthcare professionals, institutions, patients and families. Where

appropriate, specific ethical issues related to the specific guideline sections can be addressed in that section. However, PST ethical theories and principles should still be discussed in a separate part of the guidelines. Such over-reaching ethical concerns would include:

- The ethical distinction between PST and Physician Assisted Suicide and/or Euthanasia
- The use of PST in patients who are not imminently dying
- The use of PST to treat existential suffering

Proposed Guideline Process

Clinical Practice Guidelines should keep in mind that such guidelines can on the one hand describe practice as it presently occurs and on the other be prescriptive, describing how sedation should take place in practice. Our working group believes a prescriptive document to standardize Canadian practice is appropriate. Information on current Canadian PST practice is scarce, and the plan is to obtain this by a survey of Canadian palliative care physician. Based on the literature any survey and guidelines should address the following topics:

- Definitions
- Indications
- Aims
- Decision-making
- Informed consent
- Drugs and administration
- Cultural perspectives
- Ethical perspectives
- Monitoring and outcomes

The development of a preliminary set of guidelines is being supported by the Canadian Society of Palliative Care Physicians and will be vetted throughout the palliative care and ethics community locally and internationally for comment and input. The preliminary draft of this document could be available in November of this year – with a consensus process beginning shortly thereafter.

Submitted by Blair Henry, Member of the Canadian PST Consensus Guideline Working Group

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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 in this regard.

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