

Hope for a Cure, or Fear of a Curse?

National Health Charity Leaders and the
Ethical Dilemmas of Emergent Genomic Technologies

Karen L. Ormerod

President and CEO, Osteoporosis Society of Canada
Formerly Executive Director, ALS Society of Ontario



McGill-
McConnell Program:
Master of
Management
for National Voluntary Sector Leaders

McGill University, Montreal, Canada

February 2003

Copyright 2003, 2005 by Karen L. Ormerod

Contents

Abstract	4
Introduction	5
Methodology	6
1. The Ethical Dilemma.....	8
The Ethical Issue of Abortion.....	10
2. Embryonic Stem Cell Research.....	12
Moral Diversity.....	14
Stem Cells: An Update.....	18
3. Ethics.....	21
4. Interviews with National Health Charity Leaders	26
Suzanne Lawson	27
Cathleen Morrison	30
Jane Doe.....	30
John Doe	33
Sharon Weir	35
Ben Wendland.....	37
Yves Savoie	42
Gord Thow	45
What Does It All Mean?	50
5. What Can We Do in the Future?	53
Personal Conclusions.....	56
References	58

Abstract

It is widely acknowledged among staff and volunteer leaders of national health charities (NHCs) in Canada that the debate on the ethics of embryonic stem cell research (ESCR) represents only the beginning of a monumental ethical challenge facing humankind around the broader issues of evolving genomic technologies. Yet detailed interviews with national health charity leaders revealed that most NHCs have had little opportunity or desire to devote time and energy to the ESCR debate. In order to inform and influence government decisions and legal frameworks that might promote (or restrict) ESCR, national health charities must reflect a diversity of perspectives and opinions within the health sector, while NHC leaders must be prepared to make decisions both personally and on behalf of the organizations that they serve.

Introduction

As the Executive Director for the ALS Society of Ontario, I have a keen interest in the ethical debate that currently surrounds embryonic stem cell research (ESCR). I believe that the core ethical dilemma regarding ESCR is really part of a larger debate over the definition of “life” and who has “dominion” over life. Although this debate has been raging for a long time, the embryonic stem cells issue has polarized the debate in a different way. This polarization, I think, may be only the beginning of an era of bioethical angst.

More specifically, how will this evolving science affect the leaders of national health charities (NHCs) in Canada? How will we react personally and professionally? How will we be guided? With whom will we consult? What resources do we have? What if we just don’t agree? When does a person’s obligation to the “disease,” or to their organization, come before their conscience – or should it? And what then should they do? In my own organization we have already witnessed one example where a faith group that approached us to volunteer and donate funds pulled away when the ALS Society’s position in support of embryonic stem cell research was made known.

I had heard of similar experiences from my colleagues in the voluntary sector, and this led to the idea of researching and writing a paper about how national health charity leaders will respond to these dilemmas. I will also confront the question personally: how do I, Karen Ormerod, feel about this? How do I define life? How will I consult, confer, work and live with my personal perspective? If I am to become a national leader in this sector, how will I manage the conflicting beliefs that are raging in me even now? Hence the question that forms the title of this paper: Do we hope for a cure, or fear a curse? How will national health charity leaders in Canada respond to the ethical dilemmas arising from today’s emergent genomic technologies?

If I can ultimately suggest some “next steps” to others, steps that will assist them to have the courageous conversations demanded by these types of situations, then I think I will have really accomplished something worthwhile.

Methodology

Building on the research I conducted around the ethics of embryonic stem cell research for an earlier paper in Module 3 of the McGill-McConnell Program, this paper looks at national health charities as a collective, to see how they have handled and are now handling or plan to handle ethical dilemmas arising from today's rapidly evolving genomic technologies.

After presenting my initial reflections on the ethical dilemma, as I understand it, I will take a brief look at historical ethical issues that are similar to the present ESCR debate, namely capital punishment and abortion. I will then discuss the embryonic stem cell research debate in detail. While there is an abundance of material and literature available about the societal and national impact of the ethical issues surrounding stem cell research, there is very little available that specifically considers their impact on national health charities in Canada. I therefore decided to hold a number of discussions with national health charity leaders and staff and ask them directly what their experience has been relative to ethical debates in their organizations, what they are presently experiencing around the stem cell debate and what they think the future holds.

I was specifically interested in a number of things: First, I wanted to interview *both* staff and volunteer national leaders, to see whether there was a difference in perspective and if that difference was common among the others of the same group. Second, I was interested in learning if there is any common position among the health charities that deal with terminal illnesses, versus charities that may have less at stake in the battle around embryonic stem cell research. Third, I was curious to learn if there was any correlation of a person's religious upbringing or current religious activity to any particular view. Finally, I wondered whether there are similarities of perspective on ESCR among people who feel comfortable discussing matters of an ethical or spiritual nature with their friends and colleagues. By the same token, did people who were *not* comfortable in these types of discussions share similar viewpoints on the ESCR debate?

One problem in research was the tremendous time crunch faced by so many of my colleagues. While most expressed an interest (one staff leader of a large national health charity did not respond to my overtures), a few were unable to set aside the time to discuss the issues in depth. Of twelve people (seven staff and five volunteers),

representing seven different organizations, I ended up interviewing only eight (five staff and three volunteers) from a total of six national health charities. I think nonetheless that the interviews that I did conduct represent a reasonable cross-section of the national health charities in Canada. While all of the interviewees were offered the protection of anonymity in order to elicit honest and truthful responses, without regard for potential negative ramifications from their respective organizations, only two staff members chose to have their responses labelled anonymous.

My interviews included the national executive directors of the ALS Society of Canada, the Muscular Dystrophy of Canada and the Canadian Cystic Fibrosis Foundation, and all staff members. The two anonymous staff interviews were with the vice-president of a national health charity that works in the disability field and the executive director of a support organization for persons with a life-threatening disease. The three volunteers interviewed were the Past President of the ALS Society of Canada (who also happens to now sit on the executive of the Health Charities Council of Canada), the Past President of the Canadian Cystic Fibrosis Foundation and the President of the ALS Society of B.C.

Interviews with the national health charity leaders followed a questionnaire, and the responses were transcribed and then analyzed so as to compare and contrast the different viewpoints and sift through the responses in order to determine whether some sectoral trends were evident, or whether the respondents' experiences were so different that the national health charity could not be considered as united or even similar in its approaches to the issues. I hope to be able to draw some general conclusions and propose general recommendations that national health charity leaders might find helpful and useful, as they face the dilemmas that they already know are on the horizon. Finally, I will reflect on my own personal journey around this subject and will articulate my present thoughts and plans, both for myself and for the ALS Society.

1

The Ethical Dilemma

I think the core value at stake in the debate surrounding not only embryonic stem cell research but also all emergent genomic science is our collective definition of “life” and the question of who has authority over it. This is not the first time that our society has been divided on this definition. The legalization of abortion (which really only became an issue as surgical technology was able to develop practices which ensured that abortions could be performed safely, without harming a woman’s future ability to bear children) has been debated in the public realm only for the last fifty years. The modern “right to life” movement has always pitted the rights of the unborn or potential child directly against the rights of its mother. To many, this good-versus-evil argument was relatively clear. Why destroy one life for the convenience of another? The job of “playing God” should be left to God.

However, the embryonic stem cell debate, perhaps for the first time, pits the rights of the unborn or potential child against the rights of present and future terminally ill people. Which life is more important? What about cloning? Why not grow human tissue to harvest when needed? What is evil about trying to cure deadly diseases and free millions from painful and debilitating lives? Embryonic stem cell research is just the tip of the iceberg. With cloning and artificial reproduction looming closer daily, the societal and national implications for this type of scientific progress are daunting.

In 2001, the Institute for Global Ethics (IGE) developed a CD-ROM-based ethics training program for nonprofit organizations entitled *Leading With Values*. In the accompanying book of *Readings for Leading With Values*, the authors discuss this difference between “right versus wrong” and “right versus right.” To the former, there usually is (ultimately) only one answer; yet in reality there can be many possible answers, though no answer may be altogether “right.” An ethical dilemma is a balanced choice between two principles; but not all ethical decisions are dilemmas. The first step in ethical decision making is to determine whether or not the situation is a “right-versus-right” ethical

dilemma, or a “right-versus-wrong” *moral temptation*. While most people, faced with a choice between right and wrong, will choose to do the right thing, sometimes we will be tempted to do wrong (IGE 2001, 27).

The IGE authors list six ways to tell right from wrong. A choice is wrong if it passes none of the six tests, and probably wrong if it fails to pass at least two of them. The six tests are:

1. *The Legal Test*. Is this choice against the law?
2. *The Professional Standards Test*. Is this choice consistent with the standards of conduct promulgated by your organization? Could you defend the decision to others in your profession?
3. *The Gut-Feeling Test*. Does this choice smell or feel wrong deep within your gut? Often our intuition can select right from wrong before our brains can.
4. *The Front-Page Test*. How would you feel if your decision was headlined on the front page of your local newspaper?
5. *The Role-Model Test*. Thinking about a person whom you respect as someone who models the values you have selected as your qualities, what would he or she do if faced with this decision?
6. *The Core Values Test*. Does this choice conflict with one of your core ethical values?

In differentiating between ethical dilemmas (right versus right) and moral temptations (right versus wrong), clearly the toughest choices that we make deal with authentic ethical dilemmas, in which either choice is firmly rooted in one of our basic core values. Four dilemmas appear to be so fundamental to the right-versus-right choices that they can be called *dilemma paradigms* (IGE 2001, 30):

- Truth versus loyalty
- Individual versus community

-
- Short term versus long term
 - Justice versus mercy

The authors note that to analyze a dilemma is not to resolve it, though resolution requires us to make the most appropriate choice in the circumstances. This, they say, requires some principles for decision making (IGE 2001, 31), which will be further discussed at the end of this paper.

The Ethical Issue of Abortion

It is said that since the beginning of time, women have found ways to abort unwanted pregnancies. However, the abortion issue didn't become a societal problem until a movement to legalize abortions, in order to make them safer, began pressuring governments to take action. This put the governments in the middle of the pro-life versus pro-choice debate. Much has been written on this issue, which does not require repeating here. Suffice it to say that even though many governments have taken a stand and either directly outlawed abortions (as in Ireland), or openly permitted them to the extent that the procedure is covered under government medical insurance (as in Canada), the war against abortion continues to rage. Abortion clinics continue to come under attack and some doctors who perform abortions have paid with their lives, in spite of the protection of the law.

In fact, this whole issue is beginning to surface again in the United States, where on 23 January 2003, the *Globe and Mail* reported: "U.S. abortion foes, defenders march," marking the thirtieth anniversary of the landmark Supreme Court *Roe vs. Wade* decision, which opened the door for legalized abortions in the U.S. The foes of abortion note that President George W. Bush's Republican Party has a strong anti-abortion platform. Because that party now controls both houses of Congress as well as the White House, more restrictive legislation may have a good chance of being introduced and passed. The article further reported that in a *Washington Post*-ABC News Poll released the previous day, 57 percent of respondents said that abortion should be legal in most cases. This is far from an overwhelming majority, especially since for issues like this, the "silent majority" is likely quite large and their views are unknown.

The *Globe and Mail* article noted that it was only fifteen years ago that the Supreme Court of Canada struck down the Criminal Code provisions governing abortion. It was not the woman's "right to choose" that forced the Supreme Court to act but rather the refusal of four different juries (one in Ontario and three in Quebec) to find Dr. Henry Morgentaler guilty of performing abortions in spite of his public acknowledgement that he had done so in his private clinics. The law fell because it was held to be unfair that women be required to go before a hospital committee in order to obtain permission for an abortion, not because it was unfair for them not to have access to abortion as such. The Court then directed the government to propose another law to regulate the practice of abortion; but the Conservative government of Brian Mulroney was unable to craft one that would meet with government approval and so none has come forth since. In January 2003, *Globe and Mail* columnist Heather Mallick asked why Henry Morgentaler hadn't yet been recognized for his work in bringing abortions out of the back alleys and into modern, safe clinics. While the struggle has not been easy (his Toronto clinic was firebombed in 1992) and he continues to wear a bullet-proof vest when in public (*Globe and Mail*, 21 January 2003, A16), it is reported that Dr. Morgentaler has now headed north to Nunavut to establish abortion clinics for that under-serviced population.

This issue is worth mentioning here because for the past thirty years society has had so much conversation, debate, controversy and struggle about the ethics of abortion; yet we are still no closer to a unified approach or consensual position on the matter. How then will we fare with the more subtle intricacies and dangers of evolving genomic technologies, where there is potentially good and evil in both of these opposing positions?

2

Embryonic Stem Cell Research

For the first time in the ongoing effort to find a cure for ALS, a deadly disease for which no cure or treatment currently exists, there is real hope that stem cell research has the potential of managing or even curing this devastating disorder – and perhaps many other catastrophic diseases as well. Surely this tremendous potential of good could not be bad! However, the ethical and moral dilemmas raised are as powerful and divisive as ever. In this section I will attempt to explore and define some of these issues. While I personally support the concept of embryonic stem cell research, I do so in spite of some personal struggles, for I too fear the double-edged sword of genetic manipulation. It can be used for evil, as well as good, and who is to define evil and good? It is thus crucial to consider both sides of the moral conversation surrounding the debate – not only to clarify my position, but also to help me manage my personal competing moral values. As articulated in Frederick Bird’s paper “Strategies for Managing Moral Diversity” (2001), one way to manage moral diversity is to begin by respecting the conditions for moral discourse – or ethics as Good Conversation.

In a 2001 discussion entitled “Human stem cell research: Opportunities for health and ethical perspectives,” the Canadian Institutes of Health Research (CIHR) stated that “stem cells have a unique characteristic that distinguishes them from all other cell types derived from mammalian tissue, in that they have the ability to divide while maintaining their stem cell identity (‘self-renewal’). In addition, in response to certain stimuli, they can differentiate to form more specialized cells.” In lay terms, stem cells have the potential to become any kind of human tissue – brain cells, bone, hair, heart or skin. It is hoped by some that, by using stem cells, researchers will be able to create an environment to grow new cell types that could be used to replace tissues destroyed by diabetes, heart disease, Alzheimer’s disease, Parkinson’s disease, retinal degeneration, muscular dystrophy, spinal cord injury and so on, without the need for transplantation. If this were possible, we could well foresee a treatment or even a cure for ALS as well. Surely successful cell therapy using foetal and embryonic stem cells could revolutionize

the treatment and ultimate outcomes for a wide range of injuries and degenerative diseases (CIHR, 2001, 4).

Scientists have been studying stem cells derived from mice for the past twenty years and have learned that these cells are found at differing stages of development in a wide range of tissues, from muscle to skin. However, many also believe that the cells with the greatest potential to create other cells occur at the earliest stages of development, soon after the union of sperm and egg. These specific cells are called “totipotent,” meaning that they are capable of forming a new foetus; or “pluripotent,” meaning that the cells are able to form multiple tissues but not a complete organism. Stem cells from other organisms, such as adult nerves, skin or muscles are thought by some to have a much more restricted range of differentiation than the pluripotent cells from the early stages of development, although this belief is currently being challenged as researchers look for other, less contentious ways of obtaining stem cells for medical research (CIHR 2001).

The most contentious ethical issue arising from this research is the derivation of the stem cells. The four key sources are:

- Embryos created by in vitro fertilization that are no longer needed for fertility treatments
- Embryos created from gametes specifically for research purposes
- Foetal tissue resulting from elective abortions
- Embryos created by somatic cell nuclear transfer (transfer of a nucleus from a somatic cell into an egg from which the nucleus has been removed)

All of these sources are contentious and liable to be considered objectionable within several different ethical, moral and religious traditions.

Were it not for the source of stem cells, the scientific and medical community would in all likelihood be able to devote the appropriate resources to this research and achieve the results that the proponents of stem cell research espouse. However, since the desired and preferred source of the stem cells required to advance medical science is found in human

embryos, it is predictable that there will be significant opposition to the very essence of stem cell research because of the ethical and moral issues raised. It should be noted that ethical and moral issues form only a part of the puzzle. Other interests need also be considered, including clinical, scientific, economic, political and social. This paper will focus solely on the ethical and moral issues.

Moral Diversity

Some people believe that the human embryo is a being with full moral status and an inalienable right to life from the moment of conception. If true, this would make the use of a human embryo for research purposes morally unacceptable. This has of course been the basis for the “pro-life” movement’s ongoing rejection of abortions as an option under any circumstance.

Others consider that early human embryos are simply a collection of cells, with a moral status equivalent to any other cells in the body. This has been the position of the “pro-choice” movement’s contention that a first-trimester abortion is the cellular and moral equivalent of having one’s hair cut or nails trimmed.

Somewhere in the middle, others confer a special moral status on the embryo because of its potential to develop into a human being. In this view, the embryo has neither the full moral status of a person nor an absolute right to life. Though it has a right to protection, this right is not absolute and can be overridden – perhaps by the possibility of major benefits to humans and to society in general. This middle view is considered the “graduated approach,” expressed in Canada’s 1998 Tri-Council Policy Statement “Ethical conduct for research involving humans” (TCPS 2003; updated in 2000 and 2002), in which permitted interventions are governed by the developmental stage of the embryo. This is the basis for the TCPS recommendation that research be permitted up to fourteen day after formation of the zygote. Guidelines on the ethical conduct of research involving human subjects were first published in the late 1970s. In 1994 the federal government mandated its three main funding councils on research – the National Council on Ethics in Human Research, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council of Canada – to form a working group to develop a Joint Policy (TCPS 2003, i.1). The 1998 Policy Statement gave broad

direction on the types of experimental procedures that may be done with human embryonic material. In addition to the fourteen-day window, this direction included the provision for free and informed consent for use of the tissue, with no possibility for directed donation.

DRAFT RECOMMENDATIONS

2001

Research on existing human embryonic stem cells and other human cells or cell lines of a pluripotent nature should be fundable by CIHR, subject to full ethical review and application of the relevant sections of the *Tri-Council Policy Statement* and other applicable legislation.

Derivation, from human foetal tissue, of human germ cells and other human cells or cell lines of a pluripotent nature should be fundable by CIHR, subject to full ethical review and application of the relevant sections of the *Tri-Council Policy Statement* and other applicable legislation.

Research to derive human embryonic stem cells and other human cells or cell lines of a pluripotent nature from human embryos that remain after infertility treatments should be fundable by CIHR, subject to full ethical review and application of the relevant sections of the *Tri-Council Policy Statement* and other applicable legislation.

Creation of human embryos by *in vitro* fertilization for the purpose of deriving stem cells lines should not be supported.

CIHR should place a moratorium on its funding of the following procedures:

- Creation of embryos by somatic cell nuclear transfer into human oocytes for the purpose of deriving stem cell lines
- Research in which human pluripotent stem cells are utilized to create or contribute to human embryos
- Research in which human pluripotent stem cells are combined with an animal embryo
- Research in which animal pluripotent stem cells are combined with a human embryo

A national oversight body should be established to provide ethical review of all publicly and privately funded human embryo, foetal tissue and embryonic stem (ES) cell and embryonic germ (EG) cell research. Full ethical review should include review by both the local research ethics board and the national oversight body.

The Tri-Council Policy Statement should be reworked to take into account new areas of research on human embryos, foetal tissue and ES and EG cells.

CIHR should participate in any discussion of federal regulations relating to human embryo, foetal tissue and ES and EG cell research.

However, the Tri-council clearly stated that creating human embryos specifically for research, including cloning, was not acceptable. Among other activities specifically prohibited were sex selection for non-medical purposes; buying and selling of eggs, sperm and embryos; germ-line genetic alteration; ectogenesis (maintaining an embryo in an artificial womb); cloning of human embryos; creation of animal-human hybrids; retrieval of sperm or eggs from cadavers or foetuses for fertilization and implantation; or research involving the maturation of sperm or eggs outside the human body; and surrogacy arrangements (TCPS 2003). Since these guidelines were established prior to the emergence of the stem cell debate relative to embryonic tissue, they don't address some of the more specific issues in this debate. It was for this reason that, in the fall of 2000, the CIHR established its Working Group in Stem Cell Research to discuss issues surrounding research and to develop policies to address the concerns that were raised by the research that they fund. In 2001, the Working Group proposed seven draft recommendations for discussion (see below), but emphasized that any guidelines adopted by CIHR needed to be regularly reviewed and revised.

These deliberations and debates are not limited to Canadian society, but are weighing heavily on researchers and ethicists around the world. Expert working groups were formed in the United States, the United Kingdom, the Netherlands and Japan, each producing legislation, regulatory frameworks and research guidelines for their respective countries. In September 1999, the U.S. National Bioethics Advisory Committee issued a three-volume report, *Ethical issues in human stem cell research*, recommending that research involving the derivation and use of stem cells from embryos remaining after infertility treatments should be eligible for federal funding. This conflicted with an existing ban prohibiting the use of federal funds to support any research in which a human embryo is destroyed, imposed by Congress in 1995.

It was for this reason that the U.S. anxiously awaited President George W. Bush's address on stem cell research, which was televised live on 9 August 2001. President Bush shared with Americans his struggle in coming to a decision. Watching his address on CNN, I was impressed that he seemed to give thoughtful and careful consideration to both sides of the debate, articulating the pros and cons in a fair and equal manner. In a way, President Bush was giving voice to both sides of the moral conversation, in an attempt to help himself and the audience to understand that there is no clear moral

“correct” position. Both positions have elements that can be called morally correct and both have elements that can be described as morally corrupt. In the end, President Bush stayed somewhat in the middle – permitting research to continue on the already-existing cell lines, but prohibiting the development of new cell lines. In addition, his government has offered to aggressively fund further research on umbilical cord, placenta, adult and animal stem cells, which do not involve the same moral dilemma as embryonic stem cells. It could be argued that the Bush Administration has adopted and used the “Common Ethics Perspective” described in Fred Bird’s presentation *Strategies for managing moral diversity* (2001) as one of the alternative approaches to managing moral diversity. I believe that Mr. Bush’s speech satisfied the criteria for Common Ethics Perspective, in that he engaged in a “good conversation,” sketched the framework for the moral debate and identified historically significant moral covenants. Clearly, the conversation for the U.S. has just begun and will continue.

In April 2000 an expert working group in the United Kingdom proposed a number of recommendations relative to stem cell research, including the suggestion that research using embryos, whether created by *in vitro* fertilization or by cell nuclear replacement, be permitted. These recommendations were adopted by both houses of Parliament, taking effect on 31 January 2001. This is probably the most lenient legislation adopted so far. Other European countries have been more restrictive. In the Netherlands, embryos that are no longer required for fertility treatments may be used in research, but the use of embryos specifically created for research is prohibited. In France, legislation was passed in 1994, which prohibited any experimentation on embryos, but this was clarified in 1998 when the French parliament distinguished between embryos intended for reproduction and unneeded embryos, which would not be transplanted. The French legislators also invoked the fourteen-day window, which limits research to those supernumerary or spare embryos that are less than fourteen days old. Laws in Austria and Germany are much more restrictive, more or less prohibiting any research on human embryos. Scandinavia is more permissive, allowing research on a limited basis. Belgium, Greece, Italy and Luxembourg currently have no legislation concerning human embryo research; however, these issues are now being discussed by their governments. In Australia, research on human embryos that results in their destruction is allowed only in exceptional circumstances. Japan has enacted legislation that allows for embryonic stem cell research, but prohibits the cloning of people (CIHR 2001).

Stem Cells: An Update

The above section was written in February of 2002 and much has transpired since then. The Canadian Institutes of Health and Research (CIHR) introduced their guidelines, *Human pluripotent stem cell research: Guidelines for CIHR funded research*, in early March 2002. These guidelines applied only to proposals for human pluripotent stem cell research submitted to CIHR and not to research proposals to other public-sector funding organizations or to the private sector (CIHR 2002, 6.0). They also recommended that Health Canada establish a National Research Ethics Review Committee responsible for the review of certain categories of research, including novel and contentious areas of research, multi-centre trials and large population-based studies including international collaboration, so that all research, in both the public and private sectors, would be subjected to the same oversight.

Almost as soon as the CIHR guidelines were released there were many public responses, ranging from full support to outright condemnation. The ALS Society of Canada issued a position paper in which it confirmed its support of stem cell research within the confines established by the CIHR guidelines. The same was true for the Muscular Dystrophy Association, Parkinson Society of Canada and the Canadian Cancer Society, among others. The political parties each published their position papers, ranging from lukewarm support to some serious opposition.

In January 2003, in response to Clonaid's announcement of the birth of cloned babies, a Leger Marketing survey of 1,500 Canadians suggested that 84 percent of Canadians were against the cloning of human beings, compared with 5 percent who favoured the controversial practice. Eleven percent did not know or refused to answer. However, 53 percent of respondents said they supported the cloning of human embryos for the creation of stem cells that could be used in transplants and organ replacements or in the treatment of diseases. Thirty-two percent were against the idea. It is interesting to note that it was the 18–24 age group that was most open to human cloning, with 15 percent approving. Among people 65 and over, 2 percent were in favour and 93 percent were against (*Toronto Star*, 19 Jan 2003).

On 12 December 2002, Bill C-13, “An Act Respecting Assisted Human Reproductive Technologies and Related Research,” was introduced in the House of Commons by the

Standing Committee on Health. While much of the act confirms the recommendations of the CIHR guidelines referred to earlier, it also contains prohibitions against assisted reproduction procedures that are considered to be ethically unacceptable, such as human-animal hybrids. Other types of assisted reproduction procedures are prohibited unless carried out in accordance with a licence and the regulations, which will address health and safety concerns. The creation and use of embryos for research purposes is also addressed. Bill C-13 also created the Assisted Human Reproduction Agency of Canada, to advise the Minister of Health and to be responsible for the issuance and review of licences, collection and analysis of health reporting information and enforcement of the Act. Passage of this bill is not a foregone conclusion; already there are reports of special interest groups asking for amendments. But I believe that, for the first time, we will soon have some specific laws that will stipulate what Canadians can and cannot do in the name of research.

In September 2001, the Liu Centre for the Study of Global Issues at the University of British Columbia released the results of a 2001 meeting on ways in which Canada might contribute toward correcting the present global health research imbalance (90 percent of the global burden of disease is only attracting 10 percent of the world's total research effort). While much of this discussion paper dealt with socio-economic questions and answers, the following question and answer had disturbing implications:

QUESTION 10: How does health research become participatory in a way that is meaningful for individuals, is culturally appropriate and gender aware and achieves significant research goals? What from a Canadian perspective are the appropriate ethical reviews and how can we ensure that they are compatible with Canadian values and research guidelines, while being sensitive to the ethical concerns of other societies? What are some of the issues of research ethics that need to be addressed by funding agencies, universities REBS and ethics committees for resource limited countries?

RESPONSE (Cox): By appropriate consultation between inter-universities collaborative groups appropriate ethical standards for research could be established recognizing cultural diversity of different societies.

Although the question was carefully worded and reflected a significant understanding of the complex ethical challenge, it is amazing that the author of the response could be so naïve as to think that ethically appropriate research guidelines “recognizing the cultural

diversity of different societies” could be developed merely by arranging for some inter-university collaborative groups to consult! How can anyone think that a challenge of this magnitude could so easily be settled?

3

Ethics

The Funk & Wagnalls Standard College Dictionary defines ethics as “the study and philosophy of human conduct, with emphasis on the determination of right and wrong; the principles of right conduct, especially with reference to a specific profession, mode of life, etc.; and a treatise on morals.”

What happens when the two opposing sides each espouse valid ethical positions, which conflict directly with each other? The ethical dilemmas faced by national health charity leaders in Canada stem from the fact that, much of the time, both sides are correct. In simple fact, there is no entirely satisfactory answer that lies on either side of the middle; and even the middle ground does not necessarily yield the right answer. We are faced with multi-layered dilemmas. As leaders of NHCs we have to work with our stakeholders and try to carve out a position that sits somewhere along the continuum between the two opposing views. But even as we attempt this, our own personal biases are at play, influencing the direction and final position that our organizations will take. Is that “ethical”? And, even if we recognize this bias in advance and acknowledge it so as to encourage full debate of both “sides,” how then do we react and respond when the final position that our organization takes happens to conflict with our necessarily biased opinion? When does our obligation to the organization that we serve, whether as staff or as volunteers, mean that our personal beliefs must be ignored or compromised? How do we manage those situations?

John B. Cobb, Jr., Professor of Theology Emeritus at the Claremont School of Theology, California, wrote a moving paper entitled “Cloning: Has dominion gone too far?” Here he states that the questions around biotechnology “do not go to the heart of this issue as whether, as Christians, we can support these astonishing developments in biotechnology. The issue is not whether these advances violate moral principles. The issue is whether they are appropriate to the human vocation” (Cobb 2000, 5). Cobb goes on to say that humankind needs to examine the results of his past dominion over the natural world, the

physical world and the social world. He contends that much of our dominion over these worlds has not resulted in betterment for society in general, but typically has elevated the wealth of a few at the expense of many. Furthermore he states:

Whether we focus on human dominion over the physical world, over society, or over our own bodies, we must conclude that its consequences are ambiguous at best. Together they have reversed the relation between nature and artifice. Whereas two hundred years ago nature provided the context within which artifice did its work, today the artificial world is the context within which some patches of wilderness are allowed.

Whereas nature had attained over hundreds of millions of years great resilience in response to disturbances and catastrophes, the artificial world is far more fragile. Whereas the great diversities of ecosystems in the natural world insured that some would survive and spread if others were lost, the enormous simplifications introduced by human domination undercut this strength. *It is hard not to foresee human dominion leading to catastrophes of unprecedented proportions.* (Cobb 2000, 11)

At the very heart of this complex issue are the questions, “What is life?” and “What is life worth?” It is obvious from the above that humankind in general is divided on this issue; people may support abortion on demand, while at the same time condemning capital punishment, or vice versa. Does humankind have the moral authority to take and/or manipulate life – and if so, under what conditions? When does life really begin? Many of us have divided and mixed views. I think at the very base of the pyramid is the single question: What does life mean? Is the life of a severely deformed and mentally incapacitated person of any less value than my own? Does the fact that we can prevent the birth of “defective” humans mean that we should? Even if we can, should we “play God”?

Cobb (2000, 6) addresses this key question as follows:

Are we called to acknowledge our creatureliness, to accept God’s rule and to adjust ourselves to what that rule brings? Or are we to assert dominion over all creation, including ourselves, to make full use of the talents God has given us and to become creators of a new world?

Cobb points out that there is much in the Bible and in tradition to support either answer, and that much is ambiguous; the story of the Creation and Fall can be read either way. Initially, the creation story seems to support the claim to dominion. It differs from many

other creation myths by its accent on humans having dominion over other creatures and subduing them. Few would claim that the authors of genesis had cloning in mind when these verses were written; yet cloning may be simply an extension of the practices of control over domestic animals, and even over human bodies, which seem to express the dominion God gave us (Cobb 2000, 6).

But if we look more carefully, it is not at all clear that in the Genesis account the domestication of animals is included in “dominion,” much less their genetic alteration and creation to serve our economic needs better. In this story, domestication begins after the “fall from grace” when Adam and Eve tasted the forbidden fruit. Cobb contends that human dominion may not have meant exploitation. Since it is an expression of being created in the image of God, it may have meant that the human relation to other creatures should be like that of God to creation – one of care and support (Cobb 2000, 7).

Cobb explains that God gave man “dominion” when he was in the pure state, before the Fall. Therefore, it can be argued that man would have acted quite differently with regard to his exercise of dominion, had he remained in Eden. Once man fell from grace, of his own accord, he has chosen to take his “dominion” over others much further than God would have ever intended. Of course, there is no “right” answer here; but it is easier to understand the *question* when the dialogue is framed in a theological context.

I am reminded of an old movie that I watched as a child. The story centred on a devoutly Catholic woman’s difficult pregnancy and her ultimate inability to deliver her child. Set in a time before surgical intervention to safely deliver the child was possible, the choice facing the woman and her husband was simple. In order to save the mother’s life, the unborn child needed to be sacrificed. If the child was not sacrificed, the mother and the child would both die. I remember that the situation was set in the maternity ward of a Catholic hospital and the weight of this decision seemed cruel and devastating. The doctor felt strongly that the mother should be allowed to live: she could bear another child in the future. But the parents, their priest and nurses all felt that they could not sacrifice the life of their unborn child to save the mother. They left the decision in God’s hands – and in the movie, both the mother and the child die.

This story has stayed with me – and I remember thinking that I never wanted to be put in the position of making such a decision. Later in life, close family members made the choice of having abortions. My feelings were, and continue to be, almost cowardly. While I do not condemn others for making this decision and feel that the choice should be left to the individual, I don't know how I would react if I had to make the decision for myself. I feel it is okay for others, but even now as I write this paper refuse to decide whether I would or would not do the same thing. As a mother, I honestly believe that there is little that I would not do to save the life of one of my children. I recall that a few years ago, the press was divided in its criticism of a woman who chose to reverse a tubal ligation and have another child so that the new child would be able to donate a kidney to her elder child. I understand the mother's willingness to do this. She did not have to destroy her second child's life in order to save her other child, but what would she do if the destruction of the second child were necessary?

All of the above is to say that as human beings we must recognize that cellular manipulation, of which stem cell research is only the beginning, represents the “slippery slope” that could ultimately remove the humanness of being human. In the news again recently there have been stories about the use of animal tissue for transplantation. Is it morally acceptable to grow pigs specifically destined to be used for transplanting their kidneys into humans who would otherwise die? There are some who say, Why not? We farm pigs for food; why not use them in other ways to extend life? And if it is okay to use pigs for this purpose, why not clone humans for similar purposes? Genetic manipulation follows closely – are we getting closer and closer to Aldous Huxley's *Brave New World* in which babies are farmed and harvested in laboratories? Or will dreams of the development of a superior race revive, once our abilities to manipulate genes and genetic selection are refined further?

This “tip of the iceberg” relative to humankind's ability to manipulate life from the smallest cell to the largest animal will continue to play a major role for our voluntary sector in Canada and abroad. As leaders of various organizations that would benefit from the potential for cured diseases, as well as the international aid organizations that must deal with the potential of a further divided world of have and have-nots, we will be looked upon to provide leadership. Are the benefits of this type of science to be limited to the “first world”? Is a poor tribal woman in India not morally as important as a wealthy,

white man in the United States? How do we ensure access to all, if we ever do achieve moral consensus about the appropriateness of this type of intervention?

For the ALS Society and for myself, it is not difficult to say that we support the science, so long as it does not threaten “life.” I have only to talk to a young man or woman with ALS, who is trapped in a body that is wasting away in an unstoppable and unimaginable way, to say that I desperately want stem cell research to quickly help us find a control and a cure. It is only later, when I am alone that this conviction loses some of its ferocity. When I force myself to ask the hard questions about our “right” to use this power we have uncovered, I am less sure of my moral position.

4

Interviews with National Health Charity Leaders

I was interested to learn how other national health charity leaders felt about this whole subject and decided to develop a short survey and conduct interviews. The questionnaire included the following questions:

1. Has your organization had to respond to an ethical issue that has arisen as a result of new scientific technologies related to genomics?
2. Briefly describe how you and the organization confronted the situation/issue.
3. What was the resolution, and how was it arrived at?
4. What were the underlying larger ethical issues at stake?
5. Did your personal position differ from that of your organization?
6. If yes, how did you deal with that difference?
7. Can you foresee other ethical dilemmas on the horizon?
8. What could they be – personal or professional?
9. How do you think your organization will resolve this issue, and how will you arrive at your resolution?
10. What have you learned from dealing with ethical issues in the past that will inform the way you lead the organization through the next ones?
11. What resources are available to you to assist in these discussions?
12. What resources would you like to have available?
13. Are you a staff or volunteer leader?

-
14. Were you raised in an environment where semi or regular attendance at religious services was the norm?
 15. Do you now attend semi or regular religious services?
 16. Do you regularly read or discuss with colleagues matters of a religious, spiritual or ethical nature?

Along with this questionnaire I sent a letter to each recipient, describing the McGill-McConnell Program, the paper I was writing and requesting feedback from them as to their personal experiences. I offered the recipients the choice of remaining anonymous and was interested to know if they were a staff leader or a volunteer leader. Questions 13 through 16 were asked separately, with an explanation that I was going to try to determine if there was a correlation of answers among respondents with similar responses to these specific background questions.

Suzanne Lawson

Executive Director, ALS Society Of Canada

My first interview was with Suzanne Lawson, Executive Director for the ALS Society of Canada. Suzanne has held senior positions with the Canadian Cancer Society, Ontario Division (Education) as a volunteer and three salaried positions at the Heart & Stroke Foundation of Ontario as Director of Public Education, Director of Chapter Development and Director of Regional Services. She was at one time the Executive Director of the Arthritis Society, Ontario Division and Executive Director of Program for the Anglican Church of Canada. Recently she has announced that she is leaving the ALS Society of Canada to take up the position of Director of Volunteer Resources for the Hospital for Sick Children in Toronto.

In its research role, according to Suzanne, ALS Canada funds between \$300,000 and \$500,000 annually, as part of the Neuromuscular Research Partnership (NRP) (with MDAC and CIHR). While funding to date has been targeted at basic science, ALS Canada research policy allows for submissions for clinical research proposals. In addition, the NRP is gearing up to launch a \$5 million capital campaign, entitled “The

Next Great Step.” This campaign will target research into gene and cell therapy, as well as protein aggregation and misfolding.

When asked if the ALS Canada had already responded to an ethical issue that has arisen as a result of new scientific technologies related to genomics, Suzanne indicated that, prompted by the CIHR draft guidelines (referred to earlier), the staff and volunteer leaders of the Society felt compelled to develop a position statement. They held a conference call and decided to ask Briann Smith, a lawyer in Halifax, former President of the Society and a continuing member of their Executive Committee, to write a position paper on the CIHR guidelines. Briann’s paper, which essentially supported stem cell research within the guidelines, was shared with the Executive Committee. This position paper was then sent to the ALS Canada Board for approval in 2002. In our conversation, Suzanne confessed that the Board didn’t really grapple with the issues. She felt that the leaders were quite relieved to leave the work in Briann’s hands and were content to support the final position, because it was similar to the CIHR guidelines, which were seen as being “middle of the road”: recognizing the tremendous potential for stem cell research; supporting the limitations on creating embryos for scientific research; but permitting the use of surplus embryos. Asked if her personal position differed from the position statement adopted by the ALS Society, Suzanne indicated that it did not; however, that one senior volunteer from one of the provincial Societies did have a significant difference of opinion, one that forced him to re-examine his relationship with ALS Canada. With regard to other ethical dilemmas on the horizon, Suzanne specifically mentioned cloning and the need for ALS Canada to understand the difference between cellular cloning in laboratories for the purpose of science, versus the cloning of animals and humans for no other reason than to create something new and newsworthy. Suzanne said that already there was fear of unethical use of preliminary stem cell knowledge. At the International ALS/MND Meeting held in November 2002 in Australia, there was news that seven ALS patients had been given the opportunity to have stem cells (from an adult hand) injected into their spinal cords. The ethical concerns are that this type of “research” is not peer-reviewed, not part of a double-blind, placebo-controlled study, but more a desperate attempt to exploit even the slightest potential for success from this new science.

Suzanne said that she did not know how ALS Canada would resolve these ethical dilemmas; but she feels we need to know, in advance. She feels that we should have a planned process to follow, and is hopeful that this may be a result of the writing of this paper. When I asked her what she felt she had learned from past experiences that will inform future discussions, Suzanne said it was “how to elicit an ethical edge.”

Because of her links with the Anglican Church, Suzanne was asked to participate on a panel discussion on stem cell research hosted by the Department of Bioethics at the University of Toronto. Later, she appeared on *CBC Newsworld* on this topic, opposite a leader of a fundamental Christian denomination who is adamantly opposed to any kind of science that appears to devalue human life, including embryonic stem cell research. Suzanne wore three hats during this debate: as an executive director for a national health charity in Canada, which potentially has much to gain from the benefits of stem cell research; as a person of faith; and as the wife of a man with advanced Parkinson’s disease – another devastating disease that may be helped by this research.

After this media appearance and to ready herself for more, Suzanne, along with other leaders from two other voluntary health organizations, met with a priest – a philosopher and a professor of moral theology, who specializes in bioethics – to learn how to speak about embryonic stem cell research and to explain her position, using shared language and understanding with those people of faith who take the opposing view. Suzanne said that the process was extremely informative and worthwhile, and has made a big difference in handling subsequent interviews.

When I asked Suzanne what resources she would like to have available, she said that something like a checklist or code of ethics would be helpful. Certainly arranging forums in which ethicists would meet with board presidents, chief executive officers and executive directors would be most beneficial.

In answer to the last four questions, Suzanne confirmed that she answered this survey as a staff leader, that she had attended regular religious services as a child and continued to do so today, as a member of the Anglican Church of Canada (in addition, Suzanne’s husband is an Anglican priest).

Cathleen Morrison

Executive Director, Canadian Cystic Fibrosis Foundation

Although she was unable to participate in a full interview, Cathleen Morrison did say that the Canadian Cystic Fibrosis Foundation had developed a position paper on gene therapy in the early 1990s, after the 1989 discovery of the gene responsible for CF. The specific issues of concern raised in the paper related to prenatal and newborn diagnosis, carrier detection, the provision of genetic counselling and information and genetic therapy aimed at rectifying an inherited defect. These issues provoked much thought, reflection and discussion within the Foundation, for one thing because the volunteer president at that time was a devout Roman Catholic, who struggled with the larger issues within the context of his faith. Cathleen also indicated that the board would be confirming a position statement on stem cell research at its upcoming meeting, which would be similar in content to the 1990 brief.

Jane Doe

Vice-President Operations, National Health/Disability Charity

As this person asked that she and her organization remain anonymous, she will be referred to here as “Jane Doe” and her organization as “the Agency.”

The Agency is a national organization whose mission is to provide services to the people affected by a certain disability and to encourage prevention of that disability. Jane has been at her present position for four years and prior to that was a regional director for service delivery, public awareness and fundraising; a vocational rehabilitation counsellor; a treatment worker at a group home; a child care-worker; and a teaching assistant at a Canadian university.

The Agency does not fund basic science research, but does fund applied research specifically related to technology. Research proposals are reviewed by a committee consisting of staff, professionals in the field and consumers.

This Agency has already wrestled with a significant ethical issue, which has proven to be difficult to address. Through technological innovation, a device has been developed that can assist a fairly large segment of its clients to overcome their disability. A dilemma

resulted, since many clients do not consider themselves disabled: they are merely “different” and function differently and prefer to speak of their condition as a “difference,” not a disability. The Agency was thus placed in a difficult position when it was asked to take a stand on this new technology.

Some people are born with this disability, while others acquire it during their lives. This difference also seems to separate the Agency’s clients into two groups – congenital and acquired. The congenital group is openly critical of non-disabled parents who automatically choose to use technology to “correct” the disability in a congenitally disabled child. They feel that the move to correct the defect amounts to cultural genocide, and that using the technology represents a confirmation that only the non-affected are valued by our society.

Even within this community, the dilemma is layered in terms of acceptability and extremity. It is felt by some that it is more acceptable if someone has acquired the defect and then uses the technology to correct what they have lost, than for someone born with the defect to try to use the technology to replace what they have never had. However, identity issues have also arisen. In one case, non-affected parents raised their affected young child with little or no contact with other affected people. When the new technology failed to resolve the “difference,” the child had a much more difficult time integrating with the congenitally-affected community and suffered ostracism by both affected and non-affected communities.

On the other hand, Jane told of a colleague whose “difference” had been only mild at first, but became much more severe in mid-life. Once the new technology was adopted, this person experienced a significant turnaround and was much happier in being able to function reasonably well with other non-affected people. When I asked Jane about the reaction of the congenitally affected group towards this person, she said that they tended to be respectful of his choice and didn’t judge him too harshly.

One particular example of the dilemma received significant media exposure a few years ago when an infertile couple, who were both congenitally affected by this “difference,” were planning to conceive a child through a sperm bank. What was newsworthy, and what caused some people to be concerned, was that the couple specifically wanted to

ensure that donated sperm was from a man who was also congenitally affected with the same “difference,” so as to increase the odds that the child would be similarly affected. While this made perfect sense to this couple and the affected community, the reaction from society at large tended to be outrage and indignation that anyone would actually want to have a child so affected with a disability – not a “difference.”

This was just one example of the complexity of this issue. It was important that the Agency, as service provider, should not alienate one segment of the disability community in favour of another and yet it was being pressured to take a stand relative to this new technology. In order to address the dilemma, the Agency’s board hired a university professor to explore the issue in the context of complexity theory, with the objective of establishing minimum specifications for the organization. They held three workshops where the discussions were frank and open and biases were brought to the surface. As a result, the board developed three guidelines. The first would promote reciprocal awareness, in which biases were expressed and recognized in a positive way. The second was the determination of “no-go boundaries,” which would be fully respected by the Agency, its staff and volunteers. The third was that the Agency should provide enough information for informed choice; there would be ongoing dialogue about how much information would be “enough,” and the information would be kept up to date. As a result of this process, the Agency openly supports informed choice and accepts its role as the provider of the information that makes such choice possible.

When asked if her personal position differed from her Agency’s, Jane said that she was pleased with the Agency’s resolution on informed choice, because the family’s circumstances would play a large part in a client’s decision to use the technology. As to future ethical dilemmas on the horizon, she feels that the issues will be the same. Even if science develops a way to prevent this congenital disability, does society have the right to say that the particular disability is unacceptable? For any cultural minority that is functioning in the mainstream, their greatest hope is that they can function in a barrier-free environment, not that they become part of the majority. In view of the success of the workshop approach, future dilemmas will be dealt with in a similar fashion. The majority of the board members are also clients of the agency, and they are committed to surveying consumer groups in the general public to ascertain a broader perspective. As for

resources, Jane indicated that access to professionals such as the professor they used for their workshops proved invaluable.

Jane ended the interview by saying that she had not been raised in an environment that included regular religious observances, nor did she participate in them now. While she indicated to me that she did not read or discuss issues of a spiritual or ethical nature with her colleagues, I would add that in my interactions with Jane, her sense of ethics and spirituality emanate strongly. Her belief in respect and dignity for others is profoundly evident in her manner and vocabulary and was reflected in her expressed opinions and thoughtful consideration of these topics.

John Doe

Executive Director, Provincial Health Charity

This interviewee asked that he and his organization remain anonymous. Accordingly he is referred to as “John Doe” and his organization as “the Society.”

John Doe has held his position with the Society for the past four years. Prior to this, he was with the Red Cross, two Universities and a childhood cancer organization, all in a fund-development capacity. John’s nonprofit career began when he worked for five years for the Terry Fox Foundation, organizing the Terry Fox Run.

John indicated that all research funds raised by the provincial organization are transferred to the national Society for distribution in peer-reviewed research projects. Lately the Society has invested more than \$500,000 annually in basic science research. It does not fund applied or clinical research at this time and it is not at present part of a research partnership. However, the Society has begun exploring funding partnership opportunities with the Canadian Institutes of Health Research.

John confessed that his provincial organization had not had any specific discussions relative to ESCR or any other genomic technologies. His sense is that because the Society is engaged in fighting a devastating neurological disease, which at present has no cure or control, its members would be open to anything that might hold prospects for a cure. The national Society did publicly support the 2001 CIHR guidelines. However, John said that

as long as he doesn't say the words "stem cells" or "moral debate," then nobody talks about it.

When asked if his personal perspective was similar to or the same as his organization, John indicated that he personally would have gone farther than what was proposed by the CIHR guidelines and allowed for scientific results not just on the embryos left over from *in vitro* fertilization, but also from products of conception as a result of abortion.

As for future ethical dilemmas, John agreed that cloning issues will need to be addressed, but is concerned that his organization, like many others, has so little time to devote to answering such complex questions. He feels that there will be very little debate about ESCR at their provincial level. People will just say "go for it," because there is nothing else that even looks hopeful at this time. John feels that this is permissible because they have confidence that the government will move cautiously and not let an extreme position even come to the table for discussion. So by saying, "Just go for it," they are confident that they will not be going against a fundamental moral issue. John was surprised to learn that until Bill C-13 gets passed, there are no laws currently prohibiting extreme experiments such as human cloning or human-animal hybrids.

In terms of future ethical dilemmas, John feels that his board would not necessarily accept a "no holds barred" attitude to research. However, he also thinks that they will assume that "others" will have already thought through most of the ethical debate and therefore they will be able to support whatever middle-of-the-road recommendations may come forward. To support his board's discussion, John thought that he would probably go back to Fred Bird's materials about how to manage moral conversations and use these to facilitate discussion. He would ask a volunteer to get all the information, present it to the board and then have a full discussion. However, he noted that they probably would not be able to devote much more time than an hour or so for this type of deliberation – they just don't have the resources to explore, think and reflect, as they perhaps would like. The process would have to be "time effective."

Personally, John was answering the question as a staff member. He did not attend religious services as a child, does not currently attend regular religious services and does not regularly converse with colleagues about items of a spiritual or ethical nature.

Sharon Weir

Executive Board Member, Health Charities Council of Canada

My interview with Sharon was more informal and was more of a general discussion than a question-and-answer interview – partly because I was specifically interested in discussing her key position with the Health Charities Council of Canada (HCCC). I should mention that Sharon is also a Past President of ALS Canada, who lost her father to ALS a few years ago.

Sharon opened the conversation by describing HCCC’s advocacy efforts as they met with various members of Parliament, Cabinet members and government staff around Parliament Hill in 2001. The CIHR guidelines had been previously announced, but Bill C-13 had not yet been introduced to the House. Sharon felt that this created room for an unfortunate political agenda that was being pushed by those against ESCR. As a result, the stem cell issue came up at each and every meeting with HCCC representatives. In fact Sharon’s first meeting was with Rob Merrifield, who had developed a legal interpretation against ESCR for the Canadian Alliance Party. He was much better informed about the issue than any of the HCCC representatives and Sharon realized that she would need to have more information in order to discuss the details of the issue at length with legal experts. A few weeks later, when ALS Canada held its advocacy day at Parliament Hill, again it was evident that the depth of understanding of this complex issue varied among the volunteer representatives. Sharon also felt that because the individuals involved are personally committed to finding a cure for ALS they supported the Society’s position, even if they were less sure of the position ethically. One key message came from the MPs: “Tell me more, I want to learn about this.” Sharon feels that this is an important message not only for ALS Canada, but also for HCCC. The elected government officials and some of the staff don’t feel that they have adequate information on which to base their own opinions and HCCC can take a significant role in educating the government about these important issues.

I asked Sharon if any of the members of HCCC came out against the stem cell research guidelines as proposed by the CIHR. Sharon admitted that while the HCCC provided a forum for discussion about the issue, there was unspoken intimidation present – that if you have personal issues with ESCR, you should settle those differences outside of the room, rather than voice opposition inside. While the group was encouraged to ask

questions and state opinions, most qualified their responses by stating that they were citing personal views and not positions arrived at by their organizations. Some did state that their organizations had developed position statements; others indicated that they were in the process of doing so, but again were limited by resources.

She also admitted that at ALS Canada she did not think to provide a forum for these discussions. She regrets this loss of an opportunity for people to express their opinions and tell others how they were dealing with their experiences. Sharon mentioned that subsequent to ALS Canada's day on the Hill, she learned that staff had engaged an ethicist to work with them around this issue and feels that something similar would have been very beneficial for the board prior to its meetings on Parliament Hill. In addition, Sharon thinks that the whole issue may lose ground because of the difficult world situation since 11 September 2001, and that Bill C-13 may be ignored. On the other hand, she feels that the pro-life movement, being so well organized and trained in this sort of advocacy, will leverage this strength to make it appear to the government that there is much more opposition than support for the bill and so the bill may die. She commented that opponents of ESCR had already politicized the guidelines to further their case, and that this was unfair. She feels that people who are dying of a disease, which could be curable with more research, are needlessly suffering while some use the issue as a political football.

Furthermore, Sharon fears that those opposed to stem cell research will use the Raelian announcement about cloned babies as evidence as to why all this type of research should be prohibited. She points out that the Baby Boomers have the most to fear from neurological diseases and cancer and therefore the most to gain from ESCR, which specifically offers hope that these conditions can be cured. Therefore, she feels that people who favour of this type of research must be much more vocal. We discussed briefly why there is so much silence from those in favour of ESCR and agreed that there is an element of embarrassment involved. There is a sense among some that if you come out fully in favour of the research, you don't value human life and are somehow "ungodly" – but that if you come out fully against the research, you don't want a cure. Neither is correct and so many remain silent.

Sharon feels strongly that health charities such as ALS Canada must begin having these conversations and that in order to begin we must be informed by both sides of the debate. She feels that we must openly invite the dialogue and discussion in order to explore the issues and address both sides of the problem.

Sharon ended by saying that she was raised in a strict Irish Presbyterian household, but does not attend regular services at this stage of her life. She has strong personal feelings about stem cell research, partly because a good friend of hers, who suffered from ovarian cancer and who underwent experimental stem cell therapy in the United States, seemed to respond very well to the therapy and managed to live longer with a better quality of life. Sharon remains convinced that stem cell therapy has great potential for cancer treatment, as well as for diseases like ALS. She feels that the people, who donated the materials required for *in vitro* fertilization, did so out of a desire to give life. And so, giving left-over embryonic cells to researchers rather than discarding them is still a way to give life and so honours the very intent of the donors.

Ben Wendland

ALS Society of B.C.

Ben has been President of the ALS Society of B.C. for the past two years. In addition, he is British Columbia's unit representative to the ALS Canada Board and Chair of ALS Canada's Governance Committee. Privately, Ben is a business consultant with a background in real estate. He acquires a financial interest in companies, which he then restructures for improved performance and profitability. His various projects have included a career college franchise (eventually opening five schools in B.C.), mergers and acquisitions, executive management, software, forestry, and industrial properties. He has been involved with the Better Business Bureau of B.C. and has played a significant leadership role in a number of churches to which he has belonged (he has been sitting on the board for his present church for the past twelve years). As to his connection to the ALS Society, he explained that a former partner of his contracted ALS about five years ago, quickly becoming involved with the Society as a board member. This friend then approached Ben to join him on the board. With regard to the ESCR debate, Ben quickly admits that he does not support embryonic stem cell research, because he is strongly pro-life and anti-abortion. He has problems with the whole area of reproductive technology.

He says that it wasn't that hard for him to support it, but felt it only fair to advise his board in B.C. of his personal feelings, which he did. However, he also invited Dr. Andrew Eisen, one of B.C.'s leading researchers on ALS, to share with the Board his stance on the subject. Ben had advised Dr. Eisen privately of his feelings prior to his presentation.

Ben admits that despite his personal feelings he was prepared to support the ALS Society's national position, which was to support the technology as detailed in the CIHR guidelines, because he believed that the research was now limited to the existing cell lines already in use and that no further lines could be developed. However, he noted that at present in Canada there is no law in place that says new cell lines can't be developed, and this worries him. I asked Ben if his feelings were any different with regard to the gathering of stem cells from aborted fetuses versus the leftover embryos from *in vitro* fertilization, which would go in the garbage anyway. Ben said emphatically, "No and that is the problem!" He feels that the aborted fetuses are not really a source of embryonic cells, but that they are like adult stem cells, which can be harvested from people. His one concern is that perhaps we are being told that the embryos are left over from IVF; but how do we know? His main concern is not the fact that we are using these embryos; it is the fact that we are creating them in the first place. Ben feels that this is ethically wrong. Even if clinicians say they won't create more embryos than are needed for IVF, he feels that the law of supply and demand will result in additional embryos being created to meet the increasing demands of science.

Ben said that he does not condemn people who have had abortions; good people sometimes do wrong things. He related the story about good friends of his who struggled with the abortion question. The wife had cystic fibrosis and at that time it was felt that carrying a baby could well mean disaster for her; but she became pregnant anyway and all seemed to go well. However, she accidentally became pregnant a second time, at a point where she was nearing the end of her own life and so her husband was really hoping that she would have an abortion in order to avoid shortening her life any further. Because his wife was unwilling to consider abortion, this friend approached Ben to see if Ben would help persuade his wife to have the abortion. Ben told him that he would be happy to speak with the two of them, but it would be the husband that he would be persuading to change his view, not the wife. Ben said he doesn't know how the husband

could ask the wife to live with something that she knows and believes to be wrong. The end does not justify the means. Ben adds that he was also trusting that God would heal the wife, and spare her as well as the child. Ben said his friend was disappointed, but his wife lived for about two years after the second child was born. Now his friend is so thankful that he has these daughters who are a living connection with his wife.

To Ben the underlying question is clearly the definition of life. He believes that the end never justifies the means. He believes that life begins at conception and therefore also feels that *in vitro* fertilization is wrong. Humankind should not be manipulating the creation of life, regardless of the reason. Instead of IVF, infertile couples should look at adoption, which would help to solve other social issues. The creation of life, he feels, belongs to God alone. Nor does he believe that life is the be-all and end-all; death is as much a part of life as birth is. So it is not death that Ben would fight, because he doesn't believe that we should avoid death at all costs.

Ben said that he feels it is almost impossible to try to consider ethics in a vacuum without an understanding of who God is, because without that understanding, ethics becomes what one person believes is right versus what another person believes is right, and you need to have a background against which to define your ethics. Ben added that there were probably at least two other people on the ALS B.C. Board who feel as he does. I asked him how he thinks organizations like ALS Canada can come to a decision about ethical issues like this – decisions that honour both sides and yet manage to choose one side over the other. Ben said that the Board should always have a planning session or strategy session around what the Society's public voice should be – it shouldn't be just one person deciding, who then says, "Oh, by the way, this is what our position is."

The Executive Director is always asked to speak for the organization and the primary role of the Executive Committee is to ensure that a proper planning and strategizing caucus takes place around the key issues. Ben feels that members of the Society should have an opportunity to hear what others believe and also to hear what the foundation of that belief is, or why they believe what they do. He feels that even if the Society had done that, the outcome on ESCR may have been the same, but at least everyone would be able to speak to the issue more readily. Some board members learned most of what they know about the issue when we trained for our advocacy day on Parliament Hill. At that time, the

board members were told what the official position of the Society was and were given good information about the details, but there was no discussion around whether or not the individuals present agreed with the official position. However, all present were asked to support this position, if necessary, in the interviews with government officials.

Ben said that the training session was excellent and he had four very good interviews that day, where three of the people with whom he met supported strongly the CIHR guidelines and the Society's position. However, Ben had one meeting with someone who did not support the research and Ben had a good conversation with him – one in which, despite his personal beliefs, he was arguing in support of the research.

When asked what types of resources he felt that the Society would need to foster discussion sessions, he replied that there is likely enough time to do this type of thing when the Board comes together semi-annually, but that most time is taken up with financial matters. He feels that this is an issue of the heart and that issues of the heart are important to an organization like ours. People are there because they want to make a difference and so their voices should count. These are the people we need to hear from – as they are representing themselves, and not any particular interest group.

I asked Ben how he feels the health charity sector should be influencing our legislators. How do we, as organizations with our conflicting views and thoughts, inform those who we elect, so that the laws reflect the common view? Ben answered that the government is quite good at polling and discerning popular opinion. If the issue is large enough, they organize public hearings and the results of the hearings are appended as backup to the laws. However, Ben said, for issues such as this, there really is a right and a wrong and that public opinion has nothing to do with it; therefore, the laws of the land are flawed. He admitted that he does not really count on the laws of the land for a “heart” issue. For instance, he doesn't feel that the laws of the land protect the victims of crime, so it has less chance to protect the victims of stem cell research (the embryos).

Ben said that if he could, he would change the laws and outlaw ESCR, as well as IVF and abortions. However, in the absence of this option, he would wish that the Society would have a better process to establish its position. We discussed the question of why more people aren't speaking on this issue and Ben said that he believes that many choose not to

think about heart issues, because they are painful. It's easier to go on with life and not think about it. He then surprised me by stating that if he were the Executive Director for the ALS Society of Canada, he would resign rather than support the Society's public position on ESCR. He said that he could support it in his capacity as one of the Board members, but not as a key staff person having to speak for it all the time. He feels that the level of ethical conflict is important. For this issue, he feels that he can support the Society's position without believing in it personally and therefore he is not really compromising his personal ethic. However, he thinks that there are things in life that are so important to a person that they absolutely could not do anything but walk away rather than give public support in spite of personal misgivings.

I asked Ben if, in light of these feelings, he would take on the position of President of the ALS Society of Canada (an elected volunteer position). He said yes, to which I replied that it would mean that he would still be supporting the current position. However, he said that in that most senior role he might work to alter the Society's position. As President of the Society, he would establish the process and have a voice in the process of developing a national position and then would accept the outcome, on whichever side it ends up. However, for something that would be a do-or-die issue, he would take the next step and ensure that he would be actively opposed to it and not just take a silent stance.

I asked Ben what he thought was coming down the road in terms of ethical dilemmas. He feels that topping the list is euthanasia. He fears that the need and demand for body parts for transplants will place pressure on society to hurry death. He thinks that society may determine that the greater good can be accomplished by hastening the death of some terminally ill people so that the harvested organs are in better shape than if the patient is allowed to die a natural death. He is also concerned about genetic screening and cloning. He is relieved that at least for now the idea of cloning is not popular, but fears that may change.

Ben indicated that he was raised in an environment that included regular attendance at religious services and that continues today. He also confirmed that he regularly discusses issues of a spiritual and ethical nature with colleagues and friends.

Yves Savoie

Executive Director, Muscular Dystrophy Association Of Canada (MDAC)

MDAC's mission is to allow people with neuromuscular disorders to enjoy full citizenship and participate in the life of their community; to be advocates for social change in a way that makes that possible at a policy level; and to discover therapies that will eventually eradicate these types of disorders. Yves Savoie has been National Executive Director for MDAC for the past four and a half years. Prior to that, Yves was Executive Director for the Toronto East General Hospital Foundation and has held senior positions with some Universities in a fund development capacity.

With regard to research funding, MDAC is the other partner with the ALS Society of Canada and the CIHR, forming the Neuromuscular Research Partnership (NRP) which funds basic science and has some provisions that fund applied science. This is a juried, peer-reviewed process that ensures only the very best research proposals are funded. In addition, MDAC also funds a fellowship program that supports new researchers into neuromuscular disorders.

When asked how MDAC managed the ethical debate around embryonic stem cell research, Yves responded that unlike many other health charities, they had identified this as an issue at a very early stage, perhaps because Ron Worton (who heads the Stem Cell Network) was on their board at that time. Early on, they had a series of broad consultations, which involved stakeholders from different regions; but they did not consult the 10,000 Canadians who are registered with them for services. At the end of these consultations, they did not have a perfect consensus; nor did they expect that they would have one. But they did publish articles about the discussions in MDAC newsletters. Then the Board came to a decision, knowing that there were people in disagreement, but feeling that the decision to support ESCR, regardless of Board members' personal beliefs, was compatible with the mission of the organization and that was the central issue of their deliberation – relevance to mission.

I asked Yves if the consultations were done specifically to address this issue, or if the discussions took place as only part of larger discussions. He responded that the consultations were specifically called to discuss this issue. Yves felt that the key challenge was getting a greater number of people involved – meaning that those present

would gain enough information to frame a position on their own. As it turned out, between 50 and 100 people in all were involved. There were inadequate resources to include a greater number than that. I shared with Yves my dismay that I have seen little evidence of much consultation by other charities around this issue. He admitted that there have been other issues confronting MDAC that have not involved consultation – genetic testing, for example, including the more recent IVF pre-implantation genetic testing. In these instances, the Association has taken the view that it is really a purveyor of value-free information. Yves agrees that the Association tends, in fact, to reflect the values of the pro-choice movement. They imply, by the determination that they have made, that this is a decision for the individual, no for society, to make. That is definitely a normative statement for MDAC.

The other issue that MDAC faces, which it feels is in the same category as ESCR, is the issue of invasive ventilation, either in an end-of-life setting or in an acute setting with respiratory failure. MDAC is pro-choice on this issue; but its position was not arrived at through significant consultation with the membership. We explored this issue further as I commented on a recent article that I had read from the MDA U.S. on the Web, in which a person with progressive ALS challenged the community around her by asking why she was being asked to seriously consider whether or not ventilation was an appropriate course of action. People who suffer spinal cord injuries, she noted, are not presented with such a negative perspective; they are expected to want to live, and are offered any options that will help them to live. She feels that, as an ALS patient, she is not being offered ventilation as a *positive* choice. Yves responded that, in his experience, quality of life issues are very much a part of the discussion when the doctors and the family discuss the potential results of a traumatic spinal cord injury. An interesting presentation by a Mount Sinai Hospital bioethicist to an audience at a ventilation conference showed how physicians influence these fundamental questions by imposing their own values, so that difficult choices are not really addressed systematically, but rather in terms of the values of the attending physician.

MDAC came out in full public support of ESCR just after the draft guidelines were released by CIHR and was very supportive when the final guidelines were issued. In fact, Yves mentions that MDAC's initial brief went much further than the draft or final guidelines: suggesting that the legislation be extended so as to allow for therapeutic

cloning (though only once it was proved and demonstrated to be necessary for therapeutic purposes). MDAC was concerned that the legislative framework was only for research purposes and did not seriously consider that the research might actually be successful.

Yves confirmed that his personal position did not differ from the organization. He doesn't know whether there would be dissension if he canvassed Board members on their personal views; but he does know that they had accepted the argument that, in making the decision, they had to forget about their personal views because they had a fiduciary obligation to serve the corporation. However, a great many stakeholders' opinions were solicited and many chose to make their voices heard, not only during the consultation process, but also through the committee and other networks. That was where MDAC saw diametrically opposing viewpoints – from people wanting to know what they could do to get research advanced in unregulated jurisdictions (such as Jamaica), to pro-lifers arguing (for all the reasons mentioned earlier) that ESCR was completely unacceptable. In terms of future issues, besides pre-implantation genetics for IVF, the big one coming up is the issue of health economics and the genomic divide. What are we going to do when the first gene therapies are available and only Canada's millionaires are able to access them? There will also be the issue of how to select people for participation in clinical trials. They are not only selected on the medical criteria established for the trial, but beyond that, do you make participation possible, independent of economic ability to participate? Yves feels that these issues may not be specifically about morality, but rather about social justice.

Yves then mentioned another issue that is more and more apparent and where MDAC and ALS Canada are quite different, is the question of a national health charity's ability to distribute its resources so as to make a reasonable minimum standard of service available across different jurisdictions. While MDAC has historically transferred resources from one province to another, as needed, it is being pressured to stop doing this – not in a way that would change the structure of the organization, but rather under pressure from donors, gaming commissions and others who want to see funds spent only in the community in which they are raised. Yves feels strongly that this presents significant moral dilemmas, but that some of our boards don't even see it as such.

As to how MDAC will manage these future issues, Yves feels that there is a huge appetite for the type of consultation that was used previously. Accordingly MDAC has upgraded its Social Action Working Group to full committee status. The committee is now ready for consultation and is broadly representative of the people MDAC serves, in terms of geographical distribution, language and other aspects. Yves mentioned that training is also critical; his own has ranged from the McGill-McConnell Program to an executive development course in genomics and public policy at the University of Toronto, with the funding of the Frost Foundation (which was made available because of MDAC's leadership on the stem cell front). The resources of knowledge and time are important, as are volunteer resources. The new Executive Director for MDAC Ontario now devotes 20 percent of her time as Director of Social Action. MDAC is developing structures to be able to mobilize more people around the social action work and those people who are mobilized also become ready and available for consultation if needed. It is important to understand that these volunteers will only be involved if they are consulted in the front end.

In response to the last few questions, Yves said that he was raised in an environment that meant regular attendance at religious services. He does not now attend services. He does, however, discuss ethical and spiritual matters with colleagues and friends. He said that he would be described very well as an “angry Catholic.”

Gord Thow

Past President, Canadian Cystic Fibrosis Foundation

Gord Thow has been a volunteer with the Canadian Cystic Fibrosis Foundation (CCFF) for the past twenty years – serving during the last nine years at the senior level, as national Vice-President, President and (currently) Past President. His son is 20 and has CF; he also has two daughters, who do not have CF. In terms of his career, Gord has worked for the same municipal property assessment organization for the past twenty-eight years. His current position is Director of Quality Services, reporting directly to the President and CEO.

Asked how the Canadian Cystic Fibrosis Foundation has handled past ethical dilemmas, Gord quickly mentioned the issue of genetic screening, which arose after the gene that

causes cystic fibrosis was identified in 1989. By the early 1990s the CCFE found itself embroiled in a debate around what type of genetic screening was available and what it should be offering to the families of people with cystic fibrosis – whether screening should be done for newborns, or for entire families, or even whether the general population should be screened. The next question was what the screening would mean once the results were available. At present, because there are numerous variations of the defective CF gene, screening can only confirm that the subject has the defective gene; but it cannot accurately rule out all possible defects, some which are so rare that screening techniques are not yet available to detect them.

The next ethical dilemma occurs when people are informed that they carry the CF gene. What does that mean to them? What could it mean to their unborn child? If your brother or sister has CF, does that mean that you should be tested? If your results are positive, does that mean your spouse should be tested? And if your spouse tests positive, what does that mean in terms of family planning? Should a couple then decide not to have children? If pregnancy occurs, should they consider an abortion rather than take the one-in-four chance that their child will have cystic fibrosis? Gord confirmed that the Society wrestled with these issues and referred to the brief that was presented to the Royal Commission on New Reproductive Technologies in 1990.

Although more than twelve years old, this Brief is still relevant in many ways. In the introduction, it states:

In the wake of the CF gene discovery, our members are weighing new questions and options which carry significant ethical implications. The urgent issues include prenatal and newborn diagnosis, carrier detection, the provision of genetic counselling and information and genetic therapy aimed at rectifying an inherited defect.

Our volunteers represent a broad spectrum of social, economic, political and religious opinion within Canadian society. The moral perspective of our members on the questions posed by new reproductive technologies is therefore heterogeneous. However, we believe that there is an emerging consensus on the need for great care and caution in the use of certain new technologies.

In May 2001 the Foundation sent a letter to Dr. Alan Bernstein, President of CIHR, to provide comments on the discussion paper “Human Stem Cell Research” (CIHR 2002a)

In this letter, the Foundation repeats the statement that it represents a heterogeneous perspective, but then confesses that “it is challenging for us, in the absence of an opportunity for thorough consultation with our membership, to make specific recommendations bearing on the many questions posed by the possibilities presented by stem cell research.”

Gord mentioned that the Foundation’s board, at its upcoming annual meeting in May, would be asked to approve a position statement that will be presented by the Board’s Medical/Scientific Advisory Committee (MSAC). He has not seen the document, but understands that it supports stem cell research within the guidelines published by CIHR. I asked Gord whether or not the MSAC had consulted with the membership (or others) in order to arrive at the position statement. Although he was not sure what kind of consultation had occurred, Gord said he was aware that significant consultation had taken place whenever the Foundation was dealing with ethical matters in the past – for example, the MELSI workshops, which were held when the Foundation was dealing with the genetic screening issue. The Medical Ethical & Legal Social Implications (MELSI) group was formed in the early 1990s by a number of health charities in order to facilitate consultation around the genetic screening and gene therapy issues. Gord had participated in a workshop in 1993, along with Cathleen Morrison and some other senior volunteers. In addition, Gord feels that the Foundation is well linked with similar organizations around the world and they keep tabs on what is happening in other countries as well.

Gord says that the Board will look to the MSAC for direction and while there will be discussion, he feels that it is likely that the Board will confirm what the MSAC proposes as the Society’s position. He feels that there is confidence that the MSAC will have exercised due diligence in bringing forward a position statement.

Gord believes that the position statement’s guiding principles will be very similar to the principles outlined in their 1990 brief, which included:

1. Genetic counselling and ancillary services – to be made available as requested by affected individuals.
2. Cost – the cost/benefit analysis for general population screening must demonstrate that the costs are justified.

-
3. Choice, consent and confidentiality – these are paramount and must be protected.
 4. Public education – full and detailed information must be made available to affected individuals and their families.
 5. Non-discrimination – the need to anticipate discrimination on the ground of genetic inheritance and develop appropriate approaches.

Asked about his personal feelings on these issues, Gord Thow said that he was generally in line with what the CF Foundation says; the guiding principles seemed to make sense. He says that his religion does not impact this feeling, but rather he is informed by his association with a professional organization such as the Foundation. Gord is particularly worried about the potential for discrimination based on genetic inheritance. He has two daughters, one older and the other younger than his son, who has CF. When genetic testing determined that the Thows' son carries the Delta 508 defect (which is relatively easy to detect) Gord and his wife discussed the merits of having their two daughters tested as well, to see if they were carriers of the CF gene. After much discussion, however, they decided that they would not test their daughters. They feared that this type of information might “get out” and could be used against their daughters in the future – possibly by insurance companies, but also, perhaps by universities screening applications in order to make the best “social investment” (even though carriers of the defective gene have no symptoms of CF and live normal-length lives). Instead the Thows decided that their daughters should make a personal choice to be tested when they came of age and might have decisions of their own to make about family planning. Gord said that hearing about the potential pitfalls of genetic screening through MSAC was what made them decide not to have their daughters tested.

In terms of ethical dilemmas facing the Foundation down the road, Gord said that newborn screening is again becoming an issue that will require further discussion. It is now a matter of policy in a few of the U.S. states. Again the cost factor is important. With the median age now upwards of 35 years for persons with CF, it is unclear what benefit there is to mass screenings of all newborns. Most severe cases of CF are diagnosed quite early, whereas milder cases can go undiagnosed for a few years. However, even with a later diagnosis, no evidence exists that would indicate that an earlier diagnosis and

treatment would make any difference to the outcomes. Beyond newborn screening, other issues include general population screening for genetic defects, as well as cloning.

I asked Gord whether, in his opinion, national health charities could come together as a group and, with all their heterogeneous opinions, thoughts, beliefs and perspectives, tease out one position that rests roughly midway between the extreme poles of the debate. Gord admitted that this is a tough question. He thinks that sometimes organizations get around having to draw a line in the sand themselves. On genetic screening, for example, the Foundation publicly supports informed consent, leaving the decision up to the individual. In this way, the Foundation does not alienate those who choose to have the screening, or those who choose not to have it done. He believes that the general public does not fully understand the nature and ramifications of stem cell research and cloning; and so again, by supporting informed consent, the Foundation alienates no one individually, while taking advantage of the opportunity to supply as much information as possible to anyone who requests it.

Another issue that is becoming increasingly important, and potentially divisive, to the Foundation is the question of providing material support to persons with CF. When the Foundation was formed in 1961, the average life expectancy for a child born with CF was only four years. That average has now risen to 35, and will continue to rise. The Foundation was formed with the mission: to fund research, support high quality CF care, promote public awareness of CF and raise funds for these purposes. Because persons with CF are living longer, there is an Adult CF Committee, which is a standing committee of the national Board, to deal with issues relevant to adults with CF. These adults look at the \$10 or \$11 million raised by the Foundation each year and are asking why the Foundation does not use some of those funds to support adults with CF, who must face long-term disability and its attendant financial hardships. The dilemma confronting the Foundation's leadership is that if funds are diverted from research, then finding the cure will take longer, which will mean that more people will be born with CF for a longer period of time. They feel that they wouldn't be able to help every person with CF, so funding the research is more equitable, because it will, ultimately, help everyone. To date, the Foundation has used this reasoning to maintain its current mission; but the struggle is increasing in intensity, as more and more adults with CF are coming forward and asking the Foundation for assistance.

Personally, Gord informed me that while he was raised in an environment where he attended religious services on a semi-regular basis, he now attends regularly and is a Warden of the Anglican Church. He does not discuss matters of an ethical or spiritual nature with friends and colleagues.

What Does It All Mean?

I was surprised by some of the results of these interviews – not so much by the diversity of opinion as by the difficulty of finding people who would expressly state that they were against embryonic stem cell research. I had to search for them specifically, which I did not expect. It seems that there are loud voices supporting the research and a good number of soft voices that acknowledge the dilemma but admit that they are comfortable supporting the research with some restrictions. I also think that the largest number of voices is likely silent because they don't know enough about the issue or because they are uncomfortable in exploring the issue because they really aren't sure how they stand. I am reminded of the lines in an old David Clayton Thomas song: "I swear there ain't no heaven, but I pray there ain't no hell." Many of us don't want to examine these things too closely – perhaps because it may force us to decide whether or not we believe in God.

In addition, in analyzing the results of my interviews, I was also very surprised when it became quite clear that with one or two notable exceptions, the organizations surveyed have had very little opportunity or little desire to discuss the embryonic stem cell debate specifically. While lack of resources was cited as the primary reason for this lack of consultation, I also sensed an underlying presence of denial. I don't mean that anyone denies the existence of an ethical dilemma; but I sensed rather a passive denial, or moral silence as defined by Fred Bird in *The muted conscience* (1996, 1): people are morally mute when they do not recognizably communicate their moral concerns in settings where such communicating would be fitting.

According to this definition, except for the Muscular Dystrophy Association and the ALS Society of B.C., the organizations surveyed are guilty of moral silence with regard to the embryonic stem cell debate, because we have failed to create such settings in order to have these communications. Even in ALS B.C., consultation was limited to the provincial board and was not extended to their stakeholders. It was really only the MDAC that

organized multi-stakeholder consultations and encouraged broad participation in order to elicit the full range of stakeholder perspectives from which to develop its corporate position.*

Both Gord Thow of CCFF and John Doe of “the Society” indicated that they assumed that others had the moral conversations and were ensuring that nothing unethical was happening. This is somewhat true for the ALS Society as well. Suzanne Lawson, Sharon Weir and Ben Wendland all admit that consultation and discussion have not occurred at the national level. At the provincial level, my own experience is that the issue has not yet even come up on our radar screen. Somehow we have delegated the moral conversation to others, namely the CIHR and the government. We assume that good people have worked hard to develop sound judgements and that after much thought and reflection, those same good people have published the CIHR Guidelines. Therefore, most of us feel quite comfortable in supporting these recommendations without feeling the need for a debate.

I am not sure why this delegation of ethical decision making has occurred, but I suspect it has to do with our larger society’s general discomfort with speaking about moral issues. I don’t believe that the respondents feel the issues are unimportant; in fact everyone agreed that ESCR is only the first of many ethical dilemmas on the horizon. But, my sense is that unless we have strong opinions either way (such as Yves Savoie, who felt that the CIHR Guidelines did not go far enough, and Ben Wendland, who believes that even in-vitro fertilization is ethically wrong), those of us who are less sure of our opinion are more reluctant to discuss the issue.

* I now realize that I neglected to ask Yves Savoie an important question: did MDAC organize and execute community-wide consultations on ESCR as a matter of policy, or because their stakeholders demanded them? Or was it the result of Yves’s participation in the McGill-McConnell Program (Class 1) and his work on moral silence as part of that course? While I don’t know for sure, I feel that it was more the latter than the former, especially since the ALS Society is now preparing to present a session dealing with the ethical debate and our position at our upcoming Annual General Meeting in May, which I have been asked to help organize, along with a member of ALS Canada’s Executive Committee. The idea for this workshop was mine, and it was borne from the work I have done both in the Program and in writing this paper. I now feel that we need to find a way to give voice to our moral silence; certainly I would not have felt this way had I not been influenced by the content of the McGill-McConnell Program.

I was interested to note that the final interview questions about religious training and present practices had little bearing on the respondents' positions with respect to embryonic stem cell research. I had assumed, prior to the interviews, that those who were raised in a religious environment and who continued to attend religious services would have a more conservative view of the embryonic stem cell research debate, or even oppose it outright. Yet I found that some who support the research fully were raised with religious training (Suzanne, Yves, Gord) and some were not (Ben). Some continue to participate in religious observances to a significant degree and can be found on both sides of the debate. Apparently, overt commitment to the Bible and Christian teachings does not automatically mean that one is opposed to embryonic stem cell research.

5

What Can We Do in the Future?

One of the most interesting results of this paper has been the accumulation of a number of resources that can be useful to national voluntary sector leaders as they deliberate the ethical dilemmas on the horizon. While forcing oneself to face these issues is difficult, using some of the resources may help people feel more comfortable with the process and will assist us in developing our own personal positions, as well as those of our organizations.

I have learned that we need to address our moral silence and be silent no longer. As leaders, both staff and volunteers, of national health organizations, we need to create the context and the structure for these ethical debates. We need to ensure that we engage our stakeholders as much as possible, in order to facilitate the richness of the dialogue, as MDAC did. We need to insist that the resources be available to us – if not from our own budgets, then perhaps with funding from Health Canada. With the formation of the Health Charities Council of Canada, I believe that this Council can play a significant role in championing the need for dialogue and discussion around this and other ethical dilemmas.

We need to acknowledge our fear of having courageous conversations. We must guarantee that expressing one's opinion does not open one to criticism or negative perceptions and backlash. We need to learn how to deal with the dilemmas as an organization. Referring again to the Institute for Global Ethics' *Leading With Values* material,* we are encouraged to consider three principles drawn from the traditions of

* In addition to this excellent CD-ROM-based ethics training material from the Institute for Global Ethics (which I would recommend to any organization that wants to engage its stakeholders in ethical decision-making), I would also recommend the following Web sites for further resources and material:

<http://www.ornl.gov/hgmis>

Human Genome Program

<http://www.healthcharities.ca>

Health Charities Council of Canada

<http://www.globalethics.org>

Institute for Global Ethics

moral philosophy. Of the many theories, these represent three that are useful in helping us think through the right-versus-right issues and each gives us a way to test the twin rights of a dilemma. They are:

1. **Ends-based thinking.** Known also as utilitarianism, this principle is best known by the maxim: *Do whatever produces the greatest good for the greatest number.*
2. **Rule-based thinking.** Associated with Immanuel Kant’s “categorical imperative,” meaning, “Act only on that maxim through which you can at the same time will that it should become a universal law”; or more simply, “Follow only the principle that you want everyone else to follow.”
3. **Care-based thinking.** Expressed in the Golden Rule, “Do to others what you would like them to do to you”: test your actions by putting yourself in another’s shoes and imagining how it would feel if you were the recipient, rather than the perpetrator, of your actions.

These three principles imply that there are three ways to think – and no clear vote (IGE 2000, 31). Finally, the IGE material suggests that there are nine steps or checkpoints that allow for an orderly sequence for dealing with the admittedly disorderly (and sometimes downright confusing) domain of ethical issues:

1. **Recognize that there is a moral issue.** The steps require that we identify issues needing attention, rather than brushing past them (no longer keeping morally silent).
2. **Determine the actor.** This means that we must decide whether we are involved or responsible – whether or not we are morally obligated and empowered to act.

http:// www.stemcellnetwork.ca	Stem Cell Network
http://www.liucentre.ubc.ca	Centre for the Study of Global Ethics
http://www.lcc.gc.ca	Law Commission of Canada
http://www.cihr-irsc.gc.ca	Canadian Institutes of Health Research
http://www.hc-sc.gc.ca	Health Canada – Health Policy Research
http://www.ccp.ca	Canadian Centre for Philanthropy

-
3. **Gather the relevant facts.** We need to know and understand the events and potential results of both sides of the issue.
 4. **Test for right-versus-wrong issues.** Apply the six tests referred to earlier.
 5. **Test for right-versus-right paradigms.** Determine if the dilemma is truth versus loyalty or individual versus community, etc. Bring sharply into focus the fact there it is a genuine dilemma and that it pits two deeply held core values against each other.
 6. **Apply the resolution principles.** Once the choice between the sides is clearly articulated, apply either the ends-based, rule-based or care-based principle to locate the line of reasoning that seems most relevant to the issue.
 7. **Investigate the “trilemma” option.** Is there a third way through? Or is compromise possible?
 8. **Make the decision.** This step is often overlooked because the intellectual wrestling required in the previous steps can seem exhausting, leaving little energy for the final decision.
 9. **Revisit and reflect on the decision.** When the tumult and shouting have died down, go back over the process and find out what you have learned.

However, perhaps the greatest resource we will have for ending the silence on this and other ethical issues are the graduates of the McGill-McConnell Program. We have learned how important it is to have courageous conversations and the more we converse with others, the more the benefits of these conversations will be realized by others, and the art of having the conversations will spread. If we insist on providing a forum for the conversations then others will feel more comfortable in responding in kind. It will be interesting to see how this unfolds in the sub-sector of national health charities over the next few years.

Personal Conclusions

It is clear that this paper offers no definitive answers. Humankind must move slowly and deliberately. It occurred to me recently, while watching a science fiction movie, that humankind may have envisioned this sort of dilemma eons ago. In the movie, the devil was depicted in a form that was part human and part animal – with horns, cloven hoof and a tail. This is not an unusual interpretation of the devil and evil – similar depictions have existed throughout history. In retrospect, I was led to wonder if this was not a sort of self-fulfilling prophecy for the human race? Will we, in our efforts to save a human, lose humankind? Can we ask God to help us? Who will ultimately decide when there is no right or wrong? I ended my first ethics paper by saying that my cowardly resolve is to let others decide and see what happens. I didn't want to visit the morality of the issue – I found it too disturbing.

However, I now think that this issue forces me to examine my own opinions, thoughts and attitudes, and requires me to make some decisions and choices. This I have found to be most difficult. As I have thought about the issues discussed in this paper, I realize that there are arguments on each opposing side with which I both agree and disagree. In the past this was not a problem; in fact I did not want to have to make a choice for myself. It is because I can appreciate both sides that I am quite comfortable in supporting, or at least not condemning, either view. But forcing myself to take a position and state how I feel puts me in a very uncomfortable place, and I realized that this is not fair. If many people feel as I do, how fair is it that we, though unwilling to make the decision ourselves, should ask those who govern us to make these decisions on our behalf?

And so, for my part, I will now say that I support embryonic stem cell research. I don't believe that it is wrong to use spare embryos for scientific purposes, so long as there are sufficient limitations on the science to prevent genetic manipulation for the wrong reasons. I think we will need to reflect and discuss and agree on what are the rights reasons, as well as what are wrong reasons, but I do think it's possible for this to happen. I need to better understand what science actually means when it refers to cloning. It is not simply a matter of cloning a human being “just because we can.” But I need to be better informed before I can say that I support cloning, or that I do not support cloning. And after writing this paper, I feel more comfortable in engaging others in the musing, conversation and debate.

Therefore, I have agreed to co-chair a workshop in May, when the volunteers and staff of the ALS Society of Canada will come together for their Annual Meeting of Members. This workshop will address the ALS Society's position on embryonic stem cell research in an open forum. We will use some of the material from IGE's CD-ROM Ethics Training for Nonprofits and we will invite experts on both sides of the debate to address the membership with the aim of informing and educating those present about both perspectives. We will then try to create some time and space for personal reflection, group discussion and, finally, open dialogue among all those present. It is my hope that we will not only either reaffirm our present position statement, or craft a new one, but more importantly that we will have begun only the first of what will be many debates involving ethical dilemmas. And so as they say, this is not the end, but only the beginning.

References

- ALS Association (2000). The National Institutes of Health (NIH) announces guidelines for research involving human pluripotent stem cells in *News from ALSA*. Washington, DC.
- Bird, Frederick B. (1996). Moral universals as cultural realities. In F. Neil Brady, *Ethical universals in international business*. Berlin: Springer-Verlag.
- _____ (1996) *The muted conscience: Moral silence and the practice of ethics in business*. Westport, CT and London (UK): Quorum Books.
- _____ (2001). *Strategies for managing moral diversity*. Presentation. McGill-McConnell Program. Montreal: McGill University.
- Bloc Québécois Dissenting Opinion (2001). Report on assisted reproductive technologies. Standing Committee on Health. Ottawa.
- Bora Laskin Law Library (2002). Bioethics research guide. University of Toronto.
- Brown, Glen R. (2002). A church goes into business to teach ethics to business: From corporate responsibility to social accountability. Issue Paper 6. Toronto.
- Bueckert, Dennis (2003). Controversy continues to dog bill on reproductive technologies. *Canadian Press*. Ottawa.
- Bush, George W. (2001). Remarks by the President on Stem Cell Research. The Bush Ranch. 9 August. <http://www.whitehouse.gov/news/releases/2001/08/20010809-2.html>.
- Canadian Alliance Minority Report (2001). Regulating assisted human reproduction and related research. Ottawa.
- Canadian Biotechnology Advisory Committee (2001). Biotechnology and intellectual property: Patenting of higher life forms and related Issues. *Interim Report to the Government of Canada Biotechnology Ministerial Coordinating Committee*. Ottawa.
- Canadian Cancer Society (2002). Human embryonic stem cell research guidelines announced today supported by Canadian Cancer Society and National Cancer Institute of Canada. News Release. Ottawa (4 March). http://www.cancer.ca/ccs/internet/mediareleaselist/0,,3172_210504898_348065_langId-en.html.

-
- Catholic Health Association of Canada (2001). Response of the Catholic Health Association of Canada to the discussion paper published by the Canadian Institutes of Health Research. Human Stem Cell Research: Opportunities for health and ethical perspectives. Ottawa.
- Canadian Cystic Fibrosis Foundation (1990). Brief to the Royal Commission on New Reproductive Technologies. Toronto.
- CIHR (2002). Human pluripotent stem cell research: Guidelines for CIHR-funded research. Report of the ad hoc Working Group on Stem Cell Research. Ottawa: Canadian Institutes of Health Research (January). <http://www.cihr-irsc.gc.ca/e/1489.html>.
- _____ (2001). Human stem cell research: Opportunities for health and ethical perspectives. Discussion paper. Ottawa: Canadian Institutes of Health Research (29 March). Available online at http://www.cihr-irsc.gc.ca/e/pdf_14370.htm.
- Cobb, John B., Jr. (2000). Cloning: Has dominion gone too far? At *Religion on Line* (November). <http://www.religion-online.org/showarticle.asp?title=1088>.
- Government of Canada (1989). Canada Health Act. *Consolidated Statutes and Regulations*, chapter C-6. Ottawa. <http://laws.justice.gc.ca/en/c-6/17077.html>
- _____ (2001). The next frontier: Health policy and the human genome. *Health Policy Research Bulletin* 1, no. 2 (September). Ottawa: Health Canada. <http://dsp-psd.pwgsc.gc.ca/Collection/H12-36-1-2E.pdf>.
- HCCC (2002). New direction in health: The Honourable A. Anne McLellan, *Salubris* 2, no. 1 (February 2002), 4. Ottawa: Health Charities Council of Canada. http://www.healthcharities.ca/en/newsletters/Salubris_V2_N1_E.pdf.
- Human Genome Project (2003). Ethical, legal, and social issues. Washington, DC.
- _____ (2003). Gene therapy. Washington, DC.
- IGE (2001). *Leading with values: Ethics training for nonprofits*. CD-ROM. Camden, ME: Institute for Global Ethics.
- _____ (2001). *Readings for Leading with Values*. Booklet for CD-ROM. 50 pages. Camden, ME: Institute for Global Ethics.
- Jeans, Mary Ellen (2002). Discussion paper on the Canada Health Act. Prepared for the Health Charities Council of Canada. Ottawa.
- Kidder, Rushworth M. and Martha Bracy (2001). Moral courage: A white paper. Camden, ME: Institute for Global Ethics.

-
- Liu Centre (2002). Canada and the 10/90 gap: Correcting the imbalance in global health research. *Centre for the Study of Global Issues*. Vancouver.
- Mallick, Heather (2003). Why doesn't this man have the Order of Canada? *Globe and Mail*, 18 January 2003: F1.
- Minister of Health (2002). Bill C-13: An act respecting assisted human reproductive technologies and related research. Government of Canada. Ottawa.
- National Bioethics Advisory Committee (1999). *Ethical issues in human stem cell research*. 3 vols. Springfield, VA: U.S. Department of Commerce Technology Administration, National Technical Information Service. Also available on line at <http://www.georgetown.edu/research/nrcbl/nbac/pubs.html>.
- Ontario Report to Premiers (2002). Genetics, testing and gene patenting: Charting new territory in healthcare. Toronto.
- Rossant, Dr. Janet et al (Ad Hoc Working Group on Stem Cells Research) (2001). Human stem cell research: Opportunities for health and ethical perspectives. *Canadian Institutes of Health Research*. Ottawa.
- Smith, W. B. (2001). *Stem cell research: A position paper*. ALS Society of Canada. Toronto.
- TCPS (2003) Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Including updates effective May 2000 and September 2002. Ottawa. http://www.pre.ethics.gc.ca/english/pdf/TCPS%20June2003_E.pdf.