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MESSAGE FROM THE CHAIR OF THE BOARD OF DIRECTORS

It is my great pleasure to congratulate the University of Toronto Joint Centre for Bioethics (JCB) on its outstanding first decade. The University and the Faculty of Medicine, in particular, are extremely proud of the accomplishments of the JCB.

We at the university recognize the international leadership provided by the JCB in health research and education. No other centre, program or department in our faculty contributes more successfully to this vision of excellence than the JCB. It is a model for other University interdisciplinary centres.

An external review of the JCB done in 2005 concluded that the JCB is now “one of the great bioethics programs in the world.” The reviewers note that members of the JCB have received international recognition for their research achievements. They described the amount of peer-reviewed external funding that the JCB has received for bioethics research as unprecedented.

Starting as a small, university-based centre partnered with four Toronto hospitals, the JCB has developed a unique network including the University of Toronto and 15 partner organizations. It provides a unique forum for scholars from many Faculties and disciplines, including law, medicine, public health sciences, philosophy and religion. It provides a valuable service to members, enabling them to share lessons, collaborate and tap into a wide network of expertise when needed, rather than having to replicate expertise in each institution.

In its educational work the centre has produced a whole new generation of scholars, bioethics practitioners and educators.

The integration of clinical ethics work and the willingness of the faculty to respond to Canadian and global health issues has enabled the JCB to develop meaningful research directions with outcomes that are achieving impact in terms of new health policy both nationally and globally. I believe it is making a major contribution to our health care system. The reach of the centre is really global with an ability to make a difference to world health.

The JCB has grown not only in size but also in influence. For example, it was chosen as a collaborator by the World Health Organization (WHO). The JCB engagement in the international health agenda places it in a leadership role in Canada. JCB leaders work at the highest level with the Canadian government and with numerous international groups including the African Union, UNESCO, WHO and the OECD.

All this success is due to the brilliant thinking, combined with very hard work by a great number of people in and associated with the JCB. I want to recognize all the faculty, staff and
students at the JCB, and the many people in our partner organizations for their outstanding commitment to scholarship and global improvement of health through the application of bioethics. In particular, I will single out Dr. Peter Singer for his outstanding leadership. Through his creativity and commitment he has transformed a small but important University Centre into an international leader and a model for the world.

The external review concluded by calling the JCB an academic jewel that has brought great honour and prestige to the University of Toronto. We in the University do take great pride in the JCB and are excited about its future contributions.

Catharine Whiteside  
Vice-Provost, Relations with Health Care Institutions, University of Toronto  
June 2006
I first heard of bioethics in 1978 when my high school science teacher, Doug Blakey, assigned an essay on ethics of human subject experimentation. At that time, virtually no one had heard of bioethics. In 1980, I was part of a group of medical students who organized a voluntary seminar on medical ethics at U of T, which was the precursor of the current course.

I decided to pursue bioethics as a career in 1984 when I was an intern at one of our major teaching hospitals. I was caring for a young woman who was dying of widely disseminated cervical cancer. I realized that I could rattle off 20 reasons why the phosphorus level in her blood might be low, but when it came to whether we would resuscitate her when her heart stopped, the practice was to write that order in pencil on the nursing notes. I reasoned that even if low phosphorus and death were equally important problems, the rigour with which we approached the ethical question of resuscitation could be improved.

Things have changed in the last three decades. Bioethics is now widely recognized not only among doctors, nurses, patients and families, but it has a prominent role in public discussions in the media. Doctors, nurses and other health care workers routinely receive bioethics education during their studies. Hospitals employ bioethicists and must show they have mechanisms for addressing ethical challenges to be accredited. And all the teaching hospitals fully affiliated with the University of Toronto, and many of the community teaching hospital affiliates, as well as a community based organization and a science based organization, are part of the University of Toronto Joint Centre for Bioethics.

Our central goal at the JCB is to improve the quality of care. We want to help health care providers to be able to make better decisions that produce better outcomes for patients. We aim to accomplish this mission through the full integration of bioethics in health care, from the bedside to the highest levels of health care planning.

Our vehicle for accomplishing this mission is the JCB partnership between the U of T and 15 health care and science organizations. This strategic alliance defines who we are and is a key driver of our success. Without the partnership, which is at the very core of the JCB model, we would be just another bioethics centre.

The JCB is innovative, interdisciplinary and international, and we seek to improve health care. By innovative we mean we are trying to create a space where real breakthrough thinking and action can occur.

By interdisciplinary we mean that space contains scholars from a wide variety of disciplines, as well as practitioners from a wide variety of fields. We bring together many disciplines and professional groupings to share ideas, learn and collaborate, including

MESSAGE FROM THE DIRECTOR

Peter Singer
Director, Joint Centre for Bioethics
1995-2006
philosophy, medicine, nursing, theology, law, anthropology, psychology and social work. There are ongoing dialogues, and a constant exchange of ideas and information.

By international we mean that we are, in some of our work, focused on challenges in the developing world. We feel an ethical duty to help share with less fortunate nations. It is for that reason that we have put a considerable effort into the Canadian Program on Genomics and Global Health whose mission is to harness the life sciences to improve global health equity. And, our MHSc program has built an impressive community of developing world leaders in bioethics – from whom we have learned at least as much as we have taught.

By improvement we mean we are not only focused on theory but also on moving that theory towards practical solutions that have a beneficial impact on the lives of people, in Canada and around the world. Our approach is to take knowledge from theory to practice and practice to theory. We link academic research and knowledge with field experience of people who practice clinical ethics and are at the bedside and the boardroom facing hard decisions. Our goal in doing so is to improve the experience of patients, research participants, and all those who are served by the professional communities we serve.

We focus on four key areas: clinical ethics, education, research and public outreach. Working in a world filled with ethical challenges, we have had some successes: The clinical bioethics program has evolved from helping to establish a bioethics post in each JCB affiliated hospital to making bioethics a central idea in the operation of health care organizations. We are proud of the fact that we have trained more than 100 students in our two bioethics graduate programs, many of whom have become bioethics leaders in JCB hospitals, as well in other institutions in Canada and internationally. We have been able to create and transmit new knowledge on bioethics. And, we have been able to reach out to the public, in Canada and around the world.

In particular, what makes the JCB great is its focus on “real-world” impact, such as:

• Improving the care of thousands of patients from our partner health care organizations who have had ethics consults; opening the “black box” of clinical ethics, and developing and evaluating new models for clinical ethics.
• Providing the University of Toronto Joint Centre for Bioethics Living Will free of charge on our website to more than 100,000 Canadians.
• Improving resource allocation decisions in health care organizations by developing an ethical framework.
• Providing an ethical framework for pandemic influenza planning.
• Developing mechanisms to harness new technologies for the benefit of the developing world.
• Strengthening bioethics capacity in our partner organizations, throughout Canada and the world by training 120 graduate students, and many fellows, undergraduate and professional students.
The JCB’s success reflects 10 years of hard work by many people. It has been an enormous privilege and high honour for me to have had the opportunity to lead this great centre and interact with wonderful colleagues including students. This is the group to whom I owe my main debt of thanks. I also want to express my appreciation to the JCB board and its three chairs: Arnie Aberman, David Naylor and Cathy Whiteside. Fred Lowy, the Director of the precursor to the JCB, deserves our appreciation for his major role in creating the pre-conditions for our success. Finally, I want to thank the leaders of our programs – the JCB management team – for their hard work and commitment. In this, I want to single out Sue MacRae who has helped so much to build our community.

Looking ahead, I’m sure the JCB will continue to flourish and to create an ethical future for patients in Canada and throughout the world.

Peter A. Singer, MD, MPH, FRCPC
Sun Life Financial Chair and Director
University of Toronto Joint Centre for Bioethics
WORKING FOR AN ETHICAL FUTURE
In just a decade, the University of Toronto Joint Centre for Bioethics (JCB) has grown to be one of the major bioethics centres in the world. Starting in 1995 as a small, Toronto-centred program, it has rapidly expanded in size and impact. It produces internationally-respected research, trains bioethics experts and influences public debate, professional development and government thinking and policies on the ethical aspects of health care and human well-being in Canada and overseas.

Over the years, there has been a growing demand, coming from health care professionals, institutions and society at large, for a clearly understandable ethical approach in health care. Since the 1970s, the University of Toronto (U of T) had bioethics courses and some Toronto hospitals had practicing bioethicists. In 1995, the university and four hospitals forged a strategic alliance that drew from the academic knowledge of the university and the practical experience of people working in health care. Since then, the JCB has expanded to include 15 health care and science organizations, and the organization has more than 200 members, some of them living abroad. It includes the largest multidisciplinary group of in-hospital bioethicists in Canada, and it is said to be the largest bioethics centre in the world.

HOW THE JCB WORKS

The JCB set itself the tasks of not only increasing professional expertise in the discipline of bioethics, but of changing the way society thinks about how people are treated by the health care system. It seeks to influence senior health care administrators and governments in the way they think through the ethical implications of their health care decisions. It fosters academic research, professional development and open public discussion in an effort to help everyone understand the many difficult ethical choices and build capacity across health system stakeholders. The centre seeks to have decisions made in a more open manner, in tune with widely-held values and in consultation with the public.

To stimulate debate, it deals with tough questions. These include the ethical issues of genetic testing of people, how the rights of individuals should be balanced against the common good during public health crises such as a pandemic influenza outbreak and how the dying should be treated so they do not suffer unnecessarily.

The JCB uses a mix of academic research and practical experience to find solutions to improve ethical practice in the real-world of healthcare. Ideas are exchanged and trans-
The Role of Bioethics

Whether it is a doctor or nurse at the bedside of a sick patient or a hospital administrator deciding how many beds will be made available or a minister of health trying to decide what drugs will be funded, health care systems are constantly faced with ethical choices.

Bioethics is about having a health care system in which decisions are morally right and acceptable to society. It includes treating patients in an ethical manner, making ethical decisions while conducting medical research, providing ethics education for health care professionals, operating health care institutions in an ethical manner and having an ethical foundation for health care policy decisions.

The JCB can be seen as having five major streams of activity.

1. CLINICAL BIOETHICS

There is a growing demand for bioethics expertise. Clinical bioethicists are increasingly viewed not just as experts in dealing with ethics cases involving patients and staff but also as advisors to health care institutions on issues such as priority setting, pandemic influenza and community engagement.

The JCB Clinical Ethics Group, made up of bioethicists from its partner institutions, serves as a forum and support group for its members, and responds to the needs of those organizations. The clinical bioethics platform also acts as a connector between bioethics scholars and working bioethicists, particularly in JCB partner hospitals. This stream supports research on a number of key ethical issues, and provides advice to decision-makers across the health care system. For example, the Clinical Ethics Group conducted a study on the top 10 ethical challenges Canadians face in the health system. This list enable health care workers and institutions to make decisions to improve how they deliver service to patients. In another project, the Project Examining Effectiveness in Clinical Ethics (PEECE), it has set out to identify good practices for clinical ethics.

This kind of research and support has improved the ability of individual bioethicists to do their work, but it has also had a more systemic influence. Through leadership development for clinical ethicists, ethics strategic planning, organizational ethics studies and other research, the JCB has studied, analyzed and produced a series of recommendations on how
health care institutions can be run in an ethical manner. The clinical ethics program has evolved from helping to establish a bioethics post in each hospital to making bioethics a central institutional commitment in the operation of health care organizations.

2. BIOETHICS EDUCATION

Ethics is very complex and requires a broad and varied set of skills and knowledge. The JCB has been training a growing cadre of bioethics experts through a series of education programs, lectures and other ways of increasing expertise among its members and in the bioethics community at large. It has produced a whole new generation of scholars, bioethics practitioners and educators.

The bioethics education portfolio includes undergraduate and graduate studies, professional and continuing education, and fellowships in clinical ethics and research. This approach to bioethics education is seen as a model for others. JCB members published a 28-part series, “Bioethics for Clinicians,” in the Canadian Medical Association Journal, which is a premiere source for bioethics information. This work has been translated for use in Spain and Taiwan. JCB members were instrumental in the model curricula of the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada.

More than 100 students have gone through its two bioethics graduate programs, many of whom have become bioethics leaders in JCB hospitals, as well in other institutions in Canada and internationally.

Its MHSc program has built an impressive community of developing world leaders in bioethics, who are establishing bioethics programs in their own countries. Some have started the only bioethics centre in the developing world with a specific focus on poverty. Others have created new bioethics centres in Mumbai and Durban. Jerome Singh, who is now in South Africa, launched and leads the only bioethics centre in the developing world focused on HIV. International MHSc graduates have trained a series of bioethicists from India, who are forming a core for a domestic Indian bioethics training program.

3. RESEARCH PROGRAMS

JCB members have developed research programs to understand national and international needs. They range from research on clinical issues locally to how we can use science, technology and innovation to alleviate poverty, hunger, disease and pollution; how we can allocate scarce health resources fairly; and to how we can have an ethical foundation for dealing with public health crises in any country.

The JCB has used a number of approaches to stimulate research and link to the concerns of its health care partners. Among the successful approaches the JCB was successful in motivating hospital research institutes to hire bioethics researchers. The JCB also includes clinical
ethics research programs, and transfers knowledge to the clinical setting. The Clinical Ethics Group has launched a number of research projects, in such areas as clinical ethics effectiveness, organizational ethics and rehabilitation and home care ethics. This has evolved into a successful multidisciplinary approach involving senior researchers, clinical bioethicists, clinical ethics fellows, graduate students, and research associates and assistants, all working as a team.

The JCB houses the Canadian Program on Genomics and Global Health. This program is committed to achieving global health equity by helping developing countries benefit from genomics and biotechnology to improve their living conditions. The CPGGH has strong collaborative links with scholars in other genomics, ethical, environmental, economic, legal and social issues programs of Genome Canada. Research associates and assistants, post-doctoral fellows and graduate students help to conduct CPGGH projects. It has a 15-member international advisory board and a growing research team that already has 17 members.

At a time when health care funding is under increasing pressure, it is clear that no health system can afford every service that people want it to provide. Priority setting—deciding what health services society will provide and what will not be provided—is becoming ever more important. A JCB priority setting research network is helping health care administrators better address hard choices. It has helped them by developing guidelines for setting priorities, and holding meetings to help senior officials discuss the approaches. Scholars in the priority setting network feel they are opening up the “black box” of the traditional decision-making process so patients and the public can see how choices are made, and can make informed comments. This work has led to a global priority setting network.

After the SARS (Severe Acute Respiratory Syndrome) health crisis of 2003, the JCB organized a team of experts who examined how the issue was handled from an ethical perspective. They identified a series of lessons that could improve public health approaches in the future, particularly in the case of an influenza pandemic.

4. INFORMING AND LISTENING TO THE PUBLIC

People must be informed about complex bioethics issues if they are to provide well-grounded opinions that can help decision makers who must wrestle with difficult ethical choices in health care. From media releases to the Internet to theatre, the JCB is a very public institution, making great efforts not only to produce policy papers and academic journal articles, but also to communicate through the media, so it can reach the broadest range of audiences. It also seeks ideas from public about topical ethical health issues.

In an effort to find out what the public thinks is appropriate end-of-life care, JCB researchers are holding ‘town hall’ style meetings. To get high school students thinking about ethical choices, the JCB worked with others to produce a teaching approach in which young people took on different roles in a debate about the use of stem cells. This teaching module has been sent to 4,000 Canadian high schools, and is a model for other countries. In another
project, the JCB partnered in the developing of theatre pieces that deal with controversial ethical medical issues. At the end of each piece, audience members were invited to express their opinions, and this produced research that is being used by governments in policy-making.

In a more high-tech approach, the JCB, partnering with the Centre for Global eHealth Innovation of the University Health Network, is moving to use a number of technologies, including text messaging, voice connections, web-casting and handheld devices through which people can respond to ideas in a form of continuous polling of ethical issues.

5. INFLUENCING POLICY DECISIONS FOR ETHICAL CHOICES

The JCB has a major commitment to changing public policy to favour better decisions in health care. Through its work on global health and equity issues, the JCB had the credibility that enabled it to help influence the Canadian government in 2004 to make a major commitment to global health equity by sharing medical science and research capabilities with developing countries. The prime minister said that Canada should devote at least five per cent of R&D investment to a knowledge-based approach to help less fortunate countries.

There is policy work being done in priority setting at the Ministry level through the Ontario Health & Technology Assessment Committee, and other provincial bodies, e.g., Council of Academic Hospitals of Ontario Pharmaceuticals & Therapeutics Committee. As well, there has been engagement with the Ministry of Health and Long Term Care (MOHLTC) Health Results Team on ethics & community care and organizational decision-making for Local Health Integration Networks (LHINS). Internationally, priority setting consulting is ongoing with the Child Health Nutrition & Research Institute, affiliated with the Global Forum for Health Research and the WHO.

Based on its work on SARS, the JCB developed an ethics framework for dealing with major public health crises. That work was used by the Ontario Ministry of Health in developing the provincial pandemic influenza plan, making this plan the only plan in the world with such an ethics framework. The work also influenced ethical components of pan flu plans for Toronto and for the city’s hospitals. The JCB is also being consulted by WHO on ethics and pandemic flu planning.

Work on genomics, biotechnology and nanotechnology innovation to help developing countries has drawn international attention. It has been widely cited by scientists and political figures around the world, and has influenced the development of legislation.

WORKING INTO THE FUTURE

It is a measure of the JCB’s success that its scholars have published more than 1,000 articles with some in prestigious academic journals, and obtained $50 million in research funds
from a wide variety of sources. Members of the JCB are frequent recipients of major academic awards, another measure of the regard in which they are held by their peers.

One important signal of international recognition is that JCB members have worked with the Bill & Melinda Gates Foundation in its Grand Challenges in Global Health project. The project is a major effort to address what were identified as 14 “grand challenges” in fighting diseases that disproportionately affect the poorest 2 billion people in the world. In 2005, a prominent team led by Peter Singer and James Lavery of St. Michael’s Hospital received a $10 million U.S. grant from the Bill & Melinda Gates Foundation to provide advice to the Grand Challenges in Global Health program, and to study the ethical, social and cultural issues arising out of the 43 grants awarded in the Grand Challenges program, working with ethics specialists in the developing world.

As an external review panel noted in late 2005, “…the JCB is an incredibly productive centre as evidenced by its faculty’s success in obtaining peer-reviewed grants, the high policy impact of their work, their publication record and the generally uniform praise we heard from faculty and the leaders of institutions that work closely with the JCB. By these measures, it is clear that the JCB is one of the leading bioethics centers in the world.”
ABOUT THE UNIVERSITY OF TORONTO JOINT CENTRE FOR BIOETHICS (JCB)

“The JCB is a unique network. It is a network that encourages individuals and affiliated partners to work together through research, clinical practice and education to maximize shared opportunities for growth and improvement towards an ethical climate for our healthcare system. The JCB is an impressive collection of individuals with great minds, and great spirits. That is why it is so effective.”

Sue MacRae, Deputy Director, JCB

JCB HISTORY

Bioethics in Toronto has a long and distinguished history, beginning with courses at the University of Toronto in the 1970s, and continuing in the 1980s with the creation of clinical ethics units in some hospitals. By the mid-1980s, it was clear that there was great potential for synergy by linking the various bioethics components. In 1989, the U of T formed the Centre for Bioethics with a grant from the Ontario Ministry of Health. The Centre was run by Fred Lowy (Director) and Peter Singer (Associate Director).

In 1995, the University and four Toronto hospitals created the Joint Centre for Bioethics (JCB), headed by Dr. Singer. Arnie Aberman was the first board chair. During the past decade, that partnership has grown to include 15 health care and science organizations in the Toronto area, including general and specialty hospitals, community hospitals, the Toronto Community Care Access Centre and the Ontario Genomics Institute. The JCB community includes more than 200 people, including practicing bioethicists in hospitals, academics as well as medical and legal experts.

“As someone involved in the earliest planning for the Centre for Bioethics and its evolution into the Joint Centre for Bioethics, I believe that it has met all of the expectations and hopes we had for its development and flourishing. It has become a credit to all who have kept faith with the original idea, particularly Fred Lowy and Peter Singer.”

Bernard Dickens, Scholl Professor of Health Law and Policy, Faculty of Law, U of T

Sue MacRae

Bernard Dickens
**JCB APPROACH TO BIOETHICS**

**What is bioethics?**

Ethics gives us a system of moral principles to guide the way we behave and treat others. Bioethics is the branch of ethics dealing with clinical healthcare and biological practice and research. It includes treating patients in an ethical manner, making ethical decisions in clinical research and supporting the ethics education of health care professionals and trainees. It also involves having an ethical foundation for health policy decisions, such as what treatments to fund, and operating health care institutions in an ethical manner. Bioethics examines these questions:

- Deciding *what* we should do (what decisions are morally right or acceptable).
- Explaining *why* we should do it (justifying our decision in moral terms).
- Describing *how* we should do it (the method or manner of our response).

(definition created by Barbara Secker 2006)

**Four key features of the JCB’s approach to bioethics**

1. **Innovative through public outreach and policy impact**
2. **Interdisciplinary**
3. **International**
4. **Improving health care through bioethics**

**Innovative: Outreach and public involvement**

Ethical decisions in health care must respond to needs of individuals and values held by the public at large. People must be informed about complex bioethics issues if they are to provide well-grounded opinions. This is why the JCB has a focus on public involvement. Media outreach, town hall meetings, public webcast seminars and tools such as living wills are just a few examples of the many efforts the JCB has made to engage the public in discussions of bioethics.

**Innovative: Policy and practice impact**

As well as its commitment to research and publication, transfer of bioethics knowledge and public engagement, the JCB has a major commitment to changing public policy to improve in health care. One example of policy impact is the JCB’s ability to help influence
the Canadian government in 2004 to make a major commitment to health equity by sharing medical science and research capabilities with those in need in developing countries. Another is the JCB ethics framework that was adopted by the Ontario Ministry of Health as a framework for the provincial pandemic influenza plan, making this the only such plan in the world with such an ethics framework.

“The Joint Centre for Bioethics is Canada’s leading institution to analyze, research and advise on the ethical application of new health technologies to the needs of developing and emerging market countries. In these efforts it has established a leading professional reputation which is already influencing federal science and aid policies.”

David B. Watters, President, Global Advantage Consulting Group Inc. (Ottawa) and former Assistant Deputy Minister, Department of Finance

Interdisciplinary
Over the years the many connections that have formed among individuals and organizations have created a strong, thriving community. The JCB is a model for interdisciplinary collaboration among many organizations in academia and the health care world. It provides a forum for the sharing of ideas, developing research and testing of models. The JCB uses a large Canadian and international network of experts to identify key bioethics issues, research them, develop and test recommendations, and communicate the information to the medical community, academe, decision makers and the public.

International
The JCB is a collaborating centre of the World Health Organization (WHO). It has close links to international foundations, and has had significant global impact. The JCB originally entered the international field at the urging of two members, Solly Benatar and Abdallah Daar. This led the JCB into the area of training bioethics leaders in the developing world, and into many international research collaborations. According to Peter Singer, “Our decision to move our work to include a global view has had a transformational effect on us. This has had as much effect on us at the JCB as it has for those we have sought to assist.”

“The JCB as an establishment epitomized my quest for knowledge, setting me on the fast track in ethical reasoning and reorientation in the pursuit of academic excellence. Beyond these, the JCB is a strongly homogenous family characterized by love, care and exemplary life of both faculty and administrative staff. The training is of a great boost to the capacity building necessary for meeting up my clinical and academic challenges in Nigeria.”

Bayo Adejumo, Nigeria, Fogarty International Graduate, 2005
Improving health care through bioethics: Theory to practice

A distinguishing feature of the JCB is the way it transfers research and education into health care practice. Historically, the field of bioethics has drawn from the study of ethics in universities on the one hand and the experiences of working health care practitioners on the other. These can be quite separate fields. On one hand are university scholars, who often begin with a pre-existing idea of ethics, and maintain a certain distance from actual practice. On the other hand are people who are trying to address the ethical challenges in the healthcare and biosciences in practice, but who are often cut off from the significant knowledge base in formal ethics. In most cases, very little communication flows back and forth between these two worlds. The relationship between the university and health care organization partners at the JCB enables experts from various fields to bridge this gap and to draw on both theoretical and practical approaches to improve health care.

“Strong and visionary leadership, and dedication to all aspects of bioethics as a rapidly growing field of academic and clinical activities have been characteristic features of life at the centre. Vigorous debate and open expression of different views and interests in the spirit of scholarship at the Joint Centre have enabled many to flourish.”

Solly Benatar, Visiting Professor, JCB

JCB PEOPLE

The JCB is a dynamic network of people. It is the tireless dedication, commitment, heart and inspiration of everyone at the JCB that makes the centre and the community so special. “The JCB works because of how each person affiliated with the centre realizes his/her own unique vision for ethics in themselves and their own work, and at the same time finds ways to come together, cooperate and realize a collective vision together for the overall good of ethical modern health care,” said Sue MacRae, Deputy Director.

She paid particular tribute to JCB Director Peter Singer, who is leaving at the end of his 10-year term in mid-2006. “Peter brought a special blend of exuberant energy and very high professional skill to the JCB,” said Ms. MacRae. “He developed it from a modest centre of expertise at the U of T to one of the world’s foremost bioethics centres through his own drive and his ability to bring together a first-rate team.”

Many people have worked to build the JCB. Following is a list of some of those who have made strong contributions, and to whom we owe tremendous thanks and gratitude. Please see a list of names corresponding to the groups of individuals mentioned below in Appendix 1.
• Deans of the Faculty of Medicine, including former deans Arnie Aberman and David Naylor, and the current dean, Cathy Whiteside, as well as each of the JCB board members all of whom have provided the necessary governance and support over the years to the JCB.
• The University of Toronto, our academic partner.
• Our 15 healthcare organization and science partners with whom we have engaged to further our commitment to ethical healthcare for Canadians.
  - Baycrest Centre for Geriatric Care
  - Bloorview Kids Rehab
  - Centre for Addiction and Mental Health
  - Centre for Clinical Ethics of Providence Centre, St. Joseph’s Health Centre and St. Michael’s Hospital
  - The Hospital for Sick Children
  - Humber River Regional Hospital
  - Mount Sinai Hospital
  - North York General Hospital
  - Ontario Genomics Institute
  - Sunnybrook and Women’s College Health Sciences Centre
  - Toronto Community Care Access Centre
  - Toronto East General Hospital
  - Toronto Rehabilitation Institute
  - Trillium Health Centre
  - University Health Network (Princess Margaret Hospital, Toronto General Hospital and Toronto Western Hospital)
• The 216 members, who support and further the centre’s mission in the university and health care organizations.
• The JCB management team who provide leadership to the centre and support the JCB’s core programs.
• The JCB advisory committee, who include: the clinical ethics group and the university faculty from the various departments at the University of Toronto who offer teaching and guidance to our graduate students, clinical ethics activities and research platforms, and who each play a key role in the centre’s development and success.
• The 22 clinical bioethicists who work tirelessly to apply practical models and theory to improve ethical care for patients, families and staff in our health care organizations, and who provide educational support to our students and programs.
• The 18 clinical ethics fellows who have supported our growing vision in clinical ethics training over the past five years, and who have offered much to enrich our clinical programs.
• The research teams for our core research platforms who have worked with us to deliver many important publications, projects and outreach spanning a tremendous breadth and depth.
• The hundreds of students in the undergraduate, professional, postgraduate, gradu-
ate, fellowship, and continuing education programs who keep the centre growing and deepening. A special thanks to the Fogarty program international students who have come from Africa, Asia, South America and the Middle East who have deepened our understanding of the world tremendously, and have offered so much richness to all that we do.

- The participating graduate units of the JCB: Health Policy Management, and Evaluation; Law; Institute of Medical Sciences; Nursing; Philosophy; Public Health Sciences; and Religion.
- A special thanks to Mingyao Liu, Tammy Chan, Mary Seeman, Karen Davies and Hazel Pollard from the School of Graduate Studies and the Institute of Medical Science who have offered ongoing support for the administration of our MHSc program.
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- The many national and international funders who have supported the JCB with more than $50 million in grants in these past 10 years. (See the individual research programs for lists of these funders.)
- Local collaborators, including University of Toronto Ethics Centre, the Centre for Women's Health and the Temmy Latner Centre, who have offered links to theoretical and practical content.
- Members of the administrative team past and present, led by Brenda Knowles our business manager. Staff have provided the administrative support that was essential to all that we have done over these many years. A special thanks to Rhonda Martin who was here before the JCB began over a decade ago and still serves to this day.
- All the consultants who have offered technical support to our many activities.
- The many guest speakers who have taught in our courses and seminars, and the many distinguished speakers from our endowed lecture series (see Appendix 2).

“The JCB is made up of several facets, one of which is the administrative staff. These people have kept the JCB machinery running smoothly in high gear for a decade. Each staff member has brought skills that have enhanced the Centre. They are hard working, dedicated individuals who continue to give “above and beyond.”

Brenda Knowles, Business Manager.
CLINICAL BIOETHICS

The primary aim of clinical bioethics (sometimes also called clinical ethics) is to ensure that patients and those around them, such as their families, are treated in an ethical manner. Doing this improves not only the quality of life for those who are ill and their loved ones, but also improves work life for health care staff and leads to excellence in health care and research.

Clinical bioethics grew as a discipline in recent decades, applying principles of bioethics to the clinical context in such health care settings as hospitals and home care agencies. In recent years, the requirement for clinical bioethics has become more formal. Accreditation standards in Canada require ethics training programs for health care staff and ethics approaches in health care institutions. As a result, the demand for clinical bioethics services will likely continue to increase.

Clinical bioethicists are educated and trained to assist with ethical problems arising in health care and research settings. JCB clinical bioethicists have graduate training in bioethics, and come from a variety of professional backgrounds including nursing, medicine, law, theology, philosophy, social work, psychology, anthropology, science and political theory.

The responsibilities of clinical bioethicists typically include ethics consultation (bedside, clinical and organizational), ethics teaching, policy review and development, ethics research and research ethics. Increasingly, clinical ethicists are taking on leadership roles within health care organizations, including strategic planning, clinical ethics oversight, quality improvement and supervision.

Clinical Ethics Group: community of support and action

Clinical bioethicists need a community for ongoing professional development, peer support and quality review. Even before the JCB was created in 1995, bioethicists in some Toronto hospitals were discussing issues of common concern and sharing expertise. It was not until 1999 that a plan was put in motion to develop the Clinical Ethics Group. Dr. Barbara Secker, current director of the Clinical Ethics Group, attributes the impetus for and cultivation of
this group to Sue MacRae’s leadership. “Sue has been the master builder of a real, enduring community at the Joint Centre. I remember what the JCB was like before she arrived, and I longed for the kind of community she’s helped us create in clinical bioethics,” said Dr. Secker. She added that, “in the last few years the Clinical Ethics Group has grown not only in size, but also in its collegiality, wisdom and depth. This group sustains and supports me. I could not do the work I do without this group of colleagues, and I know many others feel the same.”

The JCB Clinical Ethics Group now includes about 30 people, including 22 clinical bioethicists from its affiliated hospitals, and eight JCB fellows each year as well as others, such as Jennifer Hawkins from the University, Department of Philosophy. This represents the largest multidisciplinary group of in-hospital bioethicists in Canada, and is likely the largest clinical bioethics program in the world. The clinical bioethicists work for teaching hospitals, community hospitals, community health care organizations, and science-based organizations. Clinical bioethics programs are found in all the JCB health care partner organizations.

The Clinical Ethics Group endeavours to respond to the missions of its partner organizations, including specialty areas such as children’s and women’s health, mental health and addictions, rehabilitation and community care. It also responds to areas that need more attention, such as home care, public health, aging and end-of-life care.

One of the strengths of the JCB group is providing peer support to each other so these bioethicists can sustain their ongoing support to JCB partner organizations. The clinical ethics group meets weekly to conduct confidential case consultation review for quality assurance and educational purposes. Bioethics cases are presented from each of the affiliated hospitals in case conferences with other bioethicists, JCB fellows and senior graduate students. The group also meets for weekly bioethics rounds where bioethicists share questions, ideas and initiatives. This shared learning process gives individual bioethicists in affiliated JCB partner organization access to the insights and expertise of others in the group. The group is also using Internet technology to help link clinical ethicists across a variety of sites. Listservs allow members to use their computers to quickly pose questions to one another, helping to avoid isolation and providing peer support.

The Clinical Ethics Group, through the JCB, also has access to other forms of education, professional development and support through workshops, individual mentorship and coaching sessions, and weekly bioethics seminars. Members of the group teach in the graduate programs, and supervise graduate students in practices aimed at providing applied learning in bioethics.

A 2005 external review of the JCB praised the clinical ethics work at the JCB, saying hospital board members, administrators and bioethicists all commented on the calibre of clinical ethics and the wonderful opportunities it created, including mentoring, resources and networking. The external review said this approach helps to establish an “ethics culture” within the partner organizations.

Together, the clinical ethicists in the JCB Clinical Ethics group see a combined total of more than 1,000 ethics consultations yearly. The close partnerships with hospitals, hospital administration and the Clinical Ethics Group have created a “living laboratory” that provides
a unique opportunity for research, teaching, service and networking.

The Clinical Ethics Group seeks to improve health care by developing exemplary models of clinical ethics practice in a variety of health care and research settings, making ethics an integral part of care, particularly in its partner organizations. “We want to get people into positions to lead change to improve the ethical culture and patient experiences,” said Dr. Secker.

All the clinical ethics group members are creating innovative practices in their health care organizations, and many are known nationally for their clinical ethics work, including Christine Harrison in pediatric ethics, and Hazel Markwell, who leads perhaps the largest clinical ethics program in the network. Some are also becoming known for their specific areas of expertise in clinical ethics. They include Kerry Bowman for cultural aspects of clinical ethics and conflict resolution; Jennifer Gibson for organizational ethics; Sue MacRae for ethics effectiveness and systems change; Barbara Secker for rehabilitation and disability ethics; Linda Wright for transplant ethics; and Randi Zlotnik Shaul for research accountability. Others such as Steve Abdool, Jonathan Breslin, Eoin Connolly, Joseph Chandrakanthan, Michael Gordon, Karen Faith, Dianne Godkin, Michael Gordon, Shane Green, Philip Hebert, Doreen Ouellet, Bob Parke, Marcia Sokolowski, Frank Wagner and Shawn Winsor are also carving out unique paths in areas such as mental health, end-of-life care, women’s health, research ethics, medical error, genomics, reproduction and community care.

**What are the big clinical bioethics issues?**

Ethical issues faced by JCB members tend to fall into one of four categories:

- Decisions made at the beginning and end of life.
- Organizational ethics issues dealing with decisions involving resource allocation, disclosure of risk and conflict of interest.
- ‘Everyday’ ethics issues such as the decision-making capacity of patients, consent for treatments, truth telling about a person’s state of health, privacy, confidentiality and patient sexuality.
- Relational ethics issues that can involve communications, teamwork and boundary setting.

To get a sense of the top 10 ethical challenges in Canadian health care, the JCB surveyed the Clinical Ethics Group in Toronto, in 2004. See table below for top 10 list. Since these tough issues are the bread and butter issues ethicists deal with every day, the study asked these working bioethicists to rank the top ethical challenges facing Canadians. According to the panel, the top issue was disagreements between patients and families and healthcare providers about treatment decisions. These disagreements typically take one of two forms: health care professionals might push a treatment option (either for more or less treatment) that patients and families feel is unacceptable, or conversely patients/families may push a
Top 10 Ethical Challenges Facing Canadians

1. Disagreement between patients or their families and healthcare professionals about treatment decisions.
2. Waiting lists.
3. Access to needed healthcare resources for the aged, chronically ill and mentally ill.
4. Shortage of family physicians or primary care teams in both rural and urban settings.
5. Medical error.
6. Withholding or withdrawing life-sustaining treatment in the context of terminal or serious illness, and provision of pain medication for terminally ill patients.
7. Achieving properly informed consent.
8. Ethical issues related to subject participation in research.
9. Substitute decision-making, when a patient is incapable of making a health care decision. (Living wills.)
10. The ethics of surgical innovation, and incorporating new technologies for patient care.

The Hub and Spokes Strategy

In 2001, based on the experience of its members, the Clinical Ethics Group, working in collaboration with some of its partner hospitals, piloted a service delivery model of clinical bioethics called the Hub and Spokes Strategy. “The goal of the strategy is to embed ethics into the culture of organizations from bedside to boardroom, leading to integrated, sustainable and accountable ethics programs,” said Sue MacRae who piloted the first version of the model as a bioethicist at the University Health Network, a partner of the JCB. She said those involved with the project hope that the approach will help foster an ethical climate, strengthen ethics capacity throughout health care settings and create models in clinical bioethics that are excellent and effective.

One version of this model places the clinical ethicist and senior manager (with administrative and fellow support) as the “hub,” while clinicians and trained ethics resource personnel form a series of spokes that reach into different program or service areas of the organization to provide local visibility, access and expertise. (see figure 1). The role of those in the hub is one of leadership toward building and supporting ethics capacity throughout the institution, rather than just being seen as the ethics “centre” for an organization.

Clinical ethics fellowships

The Clinical Ethics Group, developed and implemented a Clinical Ethics Fellowship Program to assist in meeting the need for clinical ethics knowledge, experience and skills. The program, which is directed by Sue MacRae, is meant to bridge the gap between graduate education in bioethics, which usually comes with mini-
mal practical experience, and the time when a graduate becomes a practicing bioethicist in a health care organization.

“The JCB’s unique clinical and community partnerships have offered me unequalled opportunities, resources and support in enhancing my skills in clinical ethics consultation, education and research.”

Kyle Anstey, Clinical Ethics Fellow 2005-06

Over the period of one or two years, clinical ethics fellows rotate through JCB partner health care organizations, and are mentored by clinical ethicists. This allows them to gain experience in clinical and organizational ethics consultation, ethics education, research ethics, and policy review and development. The JCB Clinical Ethics Fellowship Program is the largest of its kind in Canada, and has admitted 18 fellows with a high placement rate upon graduation. “The JCB has been instrumental in facilitating and shaping my transition from ethics as an area of interest to ethics as a full-time career” says Dianne Godkin, previous fellow now hired as a Clinical Ethicist at the Centre for Clinical Ethics

Other clinical bioethics innovations

Leadership development program for clinical ethicists
As clinical ethics becomes more established in health care organizations, ethicists are increasingly being asked to participate in corporate-level discussions, and to take on management and leadership roles. Until recently, there were no leadership development programs in Canada or the United States for clinical ethicists. In December 2005, the JCB began the first program, led by Jennifer Gibson (Program Leader), Sue MacRae and Barbara Secker (Program Co-Leaders), and Prof. Joseph D’Cruz (Academic Director). The project was done in collaboration with faculty from the University of Toronto Rotman School of Management, where Prof. D’Cruz is a faculty member. The course offered to the clinical ethics group members involves sessions on leading change, people skills, the difference between leadership and management, and how to apply their learning to the leadership challenges of clinical bioethics in health care organizations.

Ethics strategic planning program
JCB partner organizations have increasingly looked to the JCB for guidance in setting long-range ethics goals and priorities. Jennifer Gibson and Sue MacRae have developed an approach to meet this need. The purpose of the JCB Ethics Strategic Planning Process is to help build ethics capacity that is integrated, sustainable and accountable in JCB-affiliated member organizations. Its objectives are:

• To develop a vision for ethics in the organization.
• To establish five-year targeted priorities, clear mechanisms, and indicators of effectiveness for the ethics function.
• To achieve strategic alignment of the ethics function with the organization’s strategic directions, including its mission, vision and values.

The process involves a full examination of the ethical issues facing each organization, the development of a vision and priorities and implementation.

The first ethics strategic planning was held in 2003 with one of the JCB partner organizations, and by the end of 2005 the ethics strategic planning process had been implemented successfully in seven JCB-affiliated organizations, with four more set to go through this process in the upcoming year.

Clinical bioethics research

Project Examining Effectiveness in Clinical Ethics (PEECE)

The field of clinical bioethics is relatively new, and good practices related to clinical bioethics services have not yet been systematically studied, evaluated or shared. Some people describe clinical bioethics practice as a “black box” because of the lack of well-documented evidence for effectiveness and for good practice in the discipline.

The Project Examining Effectiveness in Clinical Ethics (PEECE) is an innovative study designed to address this pressing need by identifying good practices for clinical ethics. PEECE involved a series of nine case studies in JCB partner hospitals across Toronto. The specific objective was to examine perceptions of effectiveness and good practice in clinical ethics through the eyes of the bio ethicists, clinical staff, hospital senior management, and patients and their families. By including the views of all key stakeholders of clinical bioethics services, this unique qualitative research project serves as a solid basis for further development of the field of clinical ethics.

“…the PEECE project signalled a turning point in the study of clinical ethics at the JCB. The rich case study data provide a solid empirical basis for the development and benchmarking of good practices in the burgeoning field of clinical ethics.”

C. Shawn Tracy, Co-ordinator, PEECE Project

Among the findings of the PEECE project was that clinical bioethics is very complex, and requires a broad and varied set of skills and knowledge. Different institutions may require different approaches to clinical ethics and clinical ethicists need to play multiple roles including a consultant, policy maker, educator, mediator and researcher. Clinical bioethicists need knowledge of ethics theory and literature, the health care system, health law, leadership skills and medical terminology. They are expected to show wisdom, impartiality, fairness, honesty and humility. They must attempt to balance competing individual, institutional, and societal needs and interests.
Another significant finding was that senior managers, including CEOs, at the nine hospitals participating in PEECE, indicated great enthusiasm and support both for the JCB and for their respective on-site clinical ethics services. Clinical bioethicists are increasingly viewed as an important voice on “boardroom” issues such as transparency, resource allocation, priority setting and accountability. Many senior managers interviewed during the study spoke of the positive impact of clinical bioethics on hospital policy development, and indicated a need for greater input from and involvement of clinical bioethics across the entire organization. Thus, the PEECE data signals an ongoing shift in the emphasis of clinical ethics services from a purely clinical role to one that is institution-wide (bedside-to-boardroom).

“I’d say the contribution that clinical ethics makes to the hospital is quite central… We rely on them to contribute to building a culture of ethical reflection.”

A senior health care manager interviewed in the PEECE study

The PEECE report made a series of recommendations. It suggested that health care organizations adopt a capacity-building approach for clinical ethics, such as the Hub and Spokes Strategy, to build clinical ethics programs that are more sustainable, accountable and integrated. The report also suggested that health care organizations develop tools and/or mechanisms to measure the impact of clinical ethics on the quality of care delivery.

Based on the results of this study, the Clinical Ethics Group has worked with accreditation authorities in Canada to assist in ensuring that hospital accreditation standards for ethics are based on the best available evidence.

Organizational ethics

Clinical bioethics, as a field within health care, has tended to focus on ethical issues in the delivery of direct patient care, research and professional practice. In recent years, ethics professionals have been asked to help with organizational ethics issues that arise in the governance and management of health care organizations. Moreover, there is growing expectation in the health sector that health care organizations will behave in an ethical manner. These developments have resulted in an expanded definition of clinical bioethics at the JCB to include these organizational ethics issues. However, there is a significant gap in the literature and in practice about what counts as organizational ethics effectiveness.

In 2005, a large organizational ethics research study was launched. Led by Dr. Jennifer Gibson (JCB Leader, Clinical and Organizational Ethics Strategic Initiatives), the study involves interviews with about 170 people (including hospital board members, CEOs, senior managers, clinical and other mid-level managers, and clinical ethicists) from 13 JCB partner organizations. The study examines three questions:

- What are the organizational ethics issues faced by the health care organizations?
- What strategies do the organizations use to address these ethical issues?
- How well do the organizations feel these strategies are working?
Dr. Gibson described how decision-makers face a number of key ethical issues in managing and governing health care organizations. While many ethical issues facing health care organizations are clearly clinical, decision-makers also face important ethical issues related to the business aspects of health care organizations (e.g., resource allocation, conflict of interest, business development, commercialization of research) and to the specifically organizational aspects of clinical issues (e.g., institutional approaches to end-of-life care decision-making, disclosure of low risk to patients, care for those without medical insurance).

“This is ground-breaking research,” said Dr. Gibson, “because it is an under-examined area that has great implications for patient care.” The goal is to provide guidance in decision-making, including executive and professional education, decision-making tools and processes, and organizational ethics consultation services to JCB hospitals.

The research findings are to be published later in 2006.

“There is a visionary force alive and at work in the JCB community that inspires a passionate and hopeful response to the challenge of living ethics in a messy world.”

Jennifer Gibson, Leader, Clinical and Organizational Ethics Strategic Initiatives

Rehabilitation and community care ethics
In contrast to most research in clinical bioethics, which focuses on ethical issues arising in acute care settings, this project examines challenges in delivering health care in rehabilitation, long-term care and community contexts. In at least three of the JCB organizations (the Toronto Rehabilitation Institute, Bloorview Kids Rehab and the Toronto Community Care Access Centre) these ethical challenges are of utmost concern.

Rehabilitation and community care ethics deals with issues arising in the areas of physical medicine, rehabilitation and community care. Rehabilitation and community care ethics research is a relatively new and rather underdeveloped sub-field of bioethics, particularly in Canada. Until fairly recently, most bioethics research focused on ethical issues arising in emergency and acute health care and research settings. This research trend in bioethics may be due to a perception that, in such contexts, ethical questions are more urgent due to their often “high-tech,” dramatic, life-and-death nature. In rehabilitation and community care contexts, where goals include improving functional outcomes, helping people live with disabilities and enhancing quality of life, ethical issues are not only plentiful, but they also are increasingly pressing due to an aging population. Social justice (together with the values of autonomy, patient-centred care and quality of life) and demographic trends require a concentrated ethics research effort in this neglected area of rehabilitation and community care.

Barbara Secker, Leader, Clinical Ethics at the Toronto Rehabilitation Institute, heads this JCB research group. She said the group took advantage of Ontario’s move to a regionalized health care system and the creation of the Local Health Integration Networks (LHINs) to propose an ethical framework for the care of people with disabilities and chronic illnesses. In a
white paper presented to the province’s Ministry of Health and Long Term Care (MOHLTC) and LHINs leadership, the JCB developed a series of composite case vignettes specific to key LHINs integration opportunities, interpreted the MOHLTC governing principles for the LHINs, and provided 10 critical success factors drawn from an analysis of the LHINs governing principles as applied to the vignettes. This white paper was the impetus for a MOHLTC think tank on ethics for LHINs and included several JCB members as expert guests.

The next project for this JCB research group is to obtain grant funding to do a study from an ethical perspective of what constitutes an “adequate” home environment for younger adults with chronic illnesses and disabilities, who must often fit into a system designed for elderly persons.

*End-of-life care*

Some 222,000 Canadians die each year and, unfortunately, the quality of end-of-life care they receive is not uniformly excellent. End-of-life care raises difficult ethical debates, and this was one of the first issues tackled by the JCB, particularly by Douglas Martin and Peter Singer. The following are a list of key JCB contributions in this early work.

- Developed a new, patient-centred model of quality end-of-life care.
- Developed a new model of advance care planning, including a living will.
- Developed a new model for addressing the issues of euthanasia and assisted suicide.

As shown in the JCB study on the top 10 challenges faced by bioethicists, disagreement between patients or families and health care providers over treatment decisions has been one of the major ethical issues in health care for the past several decades. At the end of life, conflicts over these decisions can be emotionally wrenching for both families and health care providers. Attempts to delineate situations in which health care providers were justified in withholding or withdrawing life-sustaining interventions, based on a professional determination that such interventions were futile, were ill received by families. In the mid-1990s, the JCB worked in conjunction with the U of T Critical Care Medicine Program Task Force to develop a new approach. It uses an 11-step conflict resolution process to be followed when disagreements over life-sustaining treatment arise. The knowledge generated by the research has helped improve policies, bedside approaches and medical teaching practices, including in policies in the JCB network of hospitals. Recently, the JCB organizational ethics project examined these end-of-life policies to see what impact they were having in practice in the partner hospitals. The key finding is that while these policies are useful, a deeper understanding of the patients’ perspective is needed. In the coming year, clinical ethicists Jonathan Breslin and Eoin Connolly will lead the JCB in a research project engaging the public around these end-of-life policies.

“What has been missing from previous attempts to address this issue in Canada is an attempt to engage a key stakeholder group, the public,” according to Dr. Breslin. This project will involve a town hall meeting followed by a “virtual” public engagement using
Another major initiative is the Ian Anderson Continuing Education Program in End-of-Life Care, which aims to educate 10,000 primary care physicians and specialists across Canada over a five-year period to deal with issues surrounding death and dying. Led by Dr. Laura Hawryluck, this is a joint project of the JCB, with Continuing Education of the U of T, and the Temmy Latner Centre for Palliative Care at Mount Sinai Hospital, Toronto. It covers such issues as palliative care, pain management, end-of-life decision-making, communications with patients and families and conflict resolution. One goal is to create a national network of healthcare providers within all fields of medical practice trained to care for patients who are terminally ill. To achieve this goal the Anderson program has developed extensive, innovative, open access web-based resources that can serve as ongoing reference guide to best practices. These teaching materials can be adapted to meet the educational needs of practitioners within different sub-specialties, in different settings (urban to rural) and tailored to a variety of teaching methods. The Anderson program also seeks to help to shape and remodel the attitudes towards dying among physicians, legislators, media and the public. In the last five years since its inception, the Anderson program has achieved great success and even exceeded its primary goal. The Anderson program has supported and been widely used as the foundation of many other end of life educational initiatives across the country.

The JCB has also developed specific materials to help the public grapple with ethical issues. For example, Peter Singer led the development of a living will for the JCB, a booklet that spells out what a living will is, its legal status and how to make decisions using such a document. The goal is to help improve public understanding about the need for people to make clear in advance their wishes for medical treatment when a time comes that they are no longer able to communicate. The living will is available in three languages. It has been distributed to more than 100,000 Canadians in print and through the JCB website.

**BIOETHICS EDUCATION**

The increasing demand for a clearly understandable ethical approach by health care professionals, institutions and society has created a demand for bioethics expertise. Furthermore, there is a requirement for many entering the health care field to have instruction in bioethics. Accreditation standards for health care organizations and professionals require training in ethics. However, formal bioethics education in Canada has flourished only in the past decade. There were no degrees in bioethics until recent years. It is an emerging discipline.

Over the past decade, the JCB has built and now coordinates “an impressive teaching portfolio.” Courses cover a wide range of disciplines incorporating all aspects of bioethics. The education portfolio includes undergraduate and professional education, graduate studies, continuing education, and clinical ethics and research fellowships. The JCB also trains mid-career professionals from developing nations communications technologies.
to help them to establish bioethics programs in their own countries.

Students come from a number of disciplines, including health care professionals such as doctors and nurses, as well as social workers, lawyers, philosophers and other academic. Courses also prepare people who will be planning health care systems. Teaching covers such disciplines as philosophy, medicine, nursing, public health, theology and management. The program educates people in the theory and practice of bioethics, and prepares future bioethics teachers.

The bioethics education offers people a framework to help them understand the ethical background of many difficult medical issues, ranging from end-of-life care to the decisions that governments and health care administrators make about how much and what kinds of care will be provided.

Programs are offered through the JCB in partnership with the U of T, drawing on university faculty and experts from health care organizational partners. The undergraduate and postgraduate medical curricula each have a bioethics coordinator jointly appointed and financed by the U of T Faculty of Medicine and the JCB. In nursing and in arts and science (especially the departments of philosophy and religious studies) there are staff who teach bioethics within those faculties, and who are also members of JCB.

Linking major JCB research programs to graduate education, there are courses in genomics policy developed by Abdallah Daar and Halla Thorsteinsdóttir, courses in resource allocation developed by Douglas Martin, and in public health ethics, developed by Ann Robertson and Ross Upshur.

**Undergraduate and professional studies in bioethics**

*Arts and Science*

In collaboration with the JCB, the U of T philosophy department runs a very popular undergraduate program in bioethics, that helps prepare students for careers in a range of fields, including pharmaceuticals, public health, health management and health law, or to take further specialized studies to become bio ethicists. Donald Ainslie, chair of the philosophy department, said the course is so popular that it is always oversubscribed, with a total of 800 students signed up on the three university campuses in 2006. This makes it the largest bioethics education program in Canada.

The program has its roots in a course in bioethics in 1972, and it has expanded, particularly since the creation of the JCB in 1995. Students are taught about ethical issues in such fields as medical research, death and dying, reproductive technologies and mental health. The courses give the philosophical roots of bioethics so people better understand the challenges of trying to come up with solutions.
Nursing

Nurses study both at the undergraduate and graduate levels in programs that the JCB offers in collaboration with the U of T Faculty of Nursing. There is a two year Bachelor of Science in Nursing for individuals with at least two years in an undergraduate arts and/or science program, which enrolls about 150 students a year. A number go on to graduate level studies. The courses give nursing students an ability to identify ethical issues and reach sound decisions under pressure.

Elizabeth Peter, a nursing professor at the U of T and a JCB graduate, said ethics have always been part of nursing, but the study of bioethics is becoming ever more important and complex. She cited issues such as new medical technologies and health reform. The latter, she said, has "profound implications" as nurses face increasing demands with an aging population combined with staffing cutbacks aimed at reducing health care budgets.

Medical students

As part of its education portfolio, the JCB co-supports an undergraduate medical ethics program at the U of T medical school that helps future doctors understand ethical issues and how to deal with them. Founded by Dr. Philip Hébert, the program covers a range of topics, including the ethical dimensions of various diseases, health promotion and ethics, research ethics, breaking bad news, medical error palliative and end-of-life care.

“We want to get students to analyze and think through how to deal with different cases,” said Monica Branigan, the current theme coordinator for ethics and professionalism at the University of Toronto medical school. Dr. Branigan is working to develop curriculum, and to get tutors from among working doctors to teach and to be role models for students.

The program aims not only to teach ethics, but also to get medical students to think through ethical issues in practical ways. It even uses actors to play the roles of patients and other doctors, so that students can see how ethical conflicts can arise and how they might be solved.

The goal is not only to give future doctors a better grounding in ethics, but also to encourage them to work to improve ethics in the whole health care system. “We need to approach ethics and professionalism as a systems issue,” she said. “This is about how we set up the system to support people to act in the right way.”

Postgraduate medical trainees

Working medical staff face a common set of ethical issues, such as truth telling, consent, capacity, substitute decision-making, confidentiality, conflict of interest, end-of-life issues, resource allocation and research ethics.

The JCB Postgraduate Bioethics Education program is for residents in every specialty doing their training in U of T hospitals. The program was started in the early days of the JCB, after the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada required academic health science centres to have residency training
programs to teach bioethics as a condition of accreditation. The education program is based on a “hub and spokes” model in which the JCB serves as the “hub” to coordinate postgraduate bioethics teaching, and to build capacity in postgraduate bioethics teaching in each residency program (the “spokes”).

Dr. Martin McKneally, a founder of the JCB program, said young doctors need to have a frame of reference for example, in making difficult decisions when dealing with the sick and dying and their families. In addition, they must work within health care funding limits that affect how much care and equipment doctors can provide. This leads to frustration, said Dr. McKneally, but the ethics teaching helps medical staff to understand how medical resource allocation decisions are made. “It helps them become much more constructive in their thinking,” he said. In addition to teaching ethics to young doctors, the JCB program holds workshops for those who would become bioethics teachers, and, in cooperation with the Clinician Investigator Program, led by Dr. Mel Silverman, holds conferences on ethical issues of research.

Dr. Alex Levin, who is a graduate of the JCB MHSc in Bioethics, is now the Director of Postgraduate Bioethics Education at the University. Dr. Levin feels his role, “is to provide support to all residency programs at the University of Toronto in developing the required bioethics teaching for their residents in a way that is directly responsive to the unique nature of each specialty and the ethical challenges that residents face in their day to day lives.”

**Undergraduate student bioethics initiative**

Students at the JCB are encouraged to innovate and help influence their own learning. In 2003, a group of them created the Undergraduate Bioethics Initiative. It held meetings, used stories from movies and TV shows to illustrate bioethics issues, and introduced younger students to graduate students to learn more about future possibilities for study. Among its activities, the initiative brought the 2nd Canadian National Undergraduate Bioethics Conference to the JCB in 2005. Diego Silva, one of the founders of the initiative, and now a graduate student at the JCB described how this initiative got underway. “During second year as an undergraduate student, my friend Katie and I approached Peter and asked him what the JCB could do to enhance the experience of undergrads at the Centre. He responded, “Well, what have YOU done to enhance the experience of undergrads at the Centre?” and then preceded to introduce us to different members of the JCB. I quickly learnt a lesson that day that has remained with me since (and which I think is the underlining teaching philosophy at the JCB): we’ll give you the support, but you have to make things happen. And, of course, the greatest resource the JCB has is its members, which I’m blessed to say have become some of my best friends and mentors.”

**JCB summer student program**

A summer student program has created another pathway for those interested in bioethics to participate. Up to 15 students are hired for three to four months by JCB members,
including bioethicists, staff and even graduate students who have funding. The researchers gain exposure to experienced people in the field and learn skills in such fields as research and presentation. Some get to be listed in academic publications or take on administrative roles. A number return for several years, and become part of the JCB.

“As a student interested in bioethics, the JCB summer student program was a remarkable opportunity. Being able to find summer employment in bioethics has substantially contributed both to my interest in bioethics and to my likelihood for future success in the field. In addition, the networking opportunities afforded by the JCB summer student program were unparalleled. Being surrounded by like-minded students and seasoned professionals made working at the JCB a real pleasure. I would highly recommend participating in the program to any and all students interested in bioethics.”

Isaac Z. Filaté, Summer student, 2004, 2005

Graduate study in bioethics

“As a graduate student at the JCB, I feel like I have a home. To me, the JCB is more than just a ‘place of work;’ it is a centre dedicated to the cutting edge, committed to excellence, invested in the future and devoted to its members.”

Shannon Madden, Ph.D candidate, Collaborative Program Student, Department of Health Policy Management and Education/JCB

Master of Health Science in Bioethics

“The MHSc in Bioethics is a unique program that brings together individuals from many disciplines and countries to create a community of understanding about complex issues faced by patients and more broadly decision makers in health care today. The richness of the learning experience lies not only in diversity of the students, but in the calibre of the teachers, who are open, accommodating and expert in their field. Each graduate leaves with a sense of what they can contribute to health care through bioethics. We see our role at the JCB as a place to coach, mentor and support them.”

Doreen Ouellet
MBSc Program Leader and Bioethicist, Toronto East General Hospital

The Master of Health Science in Bioethics (MHSc) program develops the clinical and educational skills of mid-career professionals. Offered through the Institute of Medical Science, this is a professional master’s degree that does not require a thesis. It is designed for practicing health professionals who wish to increase their knowledge and skills in bioethics. It prepares them for a wide range of clinical ethics roles, including: clinical teachers in bioethics, consultant bioethicists and members of ethics committees.
The course covers the philosophical, legal and religious components of bioethics. It deals with issues people will face in practice, and gives them skills in teaching, dealing with differences in culture, gender, and religion and mediation skills.

The program has drawn students from a wide range of backgrounds, including medicine, nursing, social work, applied science, midwifery, pharmacy, law and journalism. The course includes a mix of case-based practice and theory, and students are encouraged to apply their new knowledge to their current jobs.

There is an important global component to the MHSc. In 2001, the JCB received a $1 million US grant for an international stream of the MHSc from the Fogarty International Center of the U.S. National Institutes of Health. It was the first program to provide bioethics training to professionals from developing countries, and has drawn people from developing countries in Africa, Asia, South America and the Middle East. In 2004, the grant was renewed for another four years. Starting in 2005 the Eastern Mediterranean Regional Office of the World Health Organization provided $200,000 for a four-year program to support four students from the Middle East.

“I am proud to say that JCB has touched many lives across the world through knowledge sharing and sowing of the seed of deliverance from ignorance. It has addressed the pessimistic view about the possibility of practicing bioethics in Africa through its capacity building program, and support for teaching and learning bioethics in the continent. No doubt, JCB has made a difference in Africa’s move toward doing bioethics.”

Ayodele Samuel Jegede, Nigeria, Fogarty Scholar, MHSc Class, 2006

This program has enabled the JCB to train 20 graduates from the developing world, providing one of the most important legacies of the institution. JCB Director Peter Singer describes these graduates as “beacons of leadership”. Graduates now are developing a new field of bioethics in Africa, South America and South Asia. Others have become leaders in bioethics publications and medical associations. Some have started the only bioethics centre in the developing world with a specific focus on poverty. Others have created new bioethics centres in Mumbai and Durban. Jerome Singh, who is now in South Africa, launched and leads the only bioethics centre in the developing world focused on HIV. Others have trained a series of bioethicists from India, who are forming a core for a domestic Indian bioethics training program.

Collaborative Program in Bioethics

The Collaborative Program in Bioethics (CPB) is a research-stream (masters and doctoral)
program to strengthen capacity in interdisciplinary bioethics research.

The CPB prepares students who will specialize in bioethics with an emphasis on innovative interdisciplinary research and scholarship in bioethics, and trains scholars whose primary goal is to contribute original research in bioethics. Students are expected to conduct innovative research in relation to the discipline of their home departments, and to have a working knowledge of selected bioethical issues from the current viewpoint of each of the other relevant disciplines.

Introduced in 1994, the CPB has admitted more than 80 students and graduated over 50. Some 25 CPB graduates are currently working in clinical bioethics as academic faculty. Seven graduate units, including Health Policy, Management, and Evaluation; Law; Medical Science; Nursing; Philosophy; Public Health Sciences; and Religion, collaborate to offer master’s (LLM, MA, MHSc, MN, MSc) and doctoral (PhD, SJD) degrees.

Founding CPB Director Bill Harvey developed the core curriculum and served as an exemplary mentor. Now a professor emeritus, he continues to inspire JCB students as a guest lecturer and discussion group facilitator. Mary Rowell took over as CPB Director, and offered continued student support and program development. The next CPB director, Doug Martin, was successful at strengthening the CPB’s academic rigor. Current CPB Director Barbara Secker said this unique program is a leading developer of researchers producing innovative, timely bioethics knowledge across disciplinary and professional lines. She is enthusiastic about the exceptional CPB students and faculty who are working together to develop a vibrant community to foster student success.

“I have been affiliated with the JCB since 1995 both as a student in the collaborative program and as affiliated faculty. This centre and its wonderful group of gifted and caring people have been pivotal to my development as a scholar and provided tremendous support as I made the change from a clinical to an academic career. It is a truly unique environment that fosters respectful learning and exchange amongst people from various disciplines and backgrounds.”

Barbara Gibson, PhD graduate from Collaborative Program in Bioethics

Continuing education

The JCB holds conferences, a weekly bioethics seminar during the academic session (open to the public) and lectures by visiting professors. It provides students with the opportunity to participate in interest groups, rounds and colloquia on new developments. In September 2006, the JCB will host the 6th International Conference on Priorities in Health Care in Toronto. In 2007, the JCB will host a joint ethics conference: the 18th Canadian Bioethics Society conference and the 3rd International Clinical Ethics and Consultation conference.

“The JCB has been and remains an outstanding community to share experiences and ideas with a diverse set of colleagues from many different disciplines.”

Neil M. Lazar, MD, Toronto General Hospital
Clinical ethics summer institute (CESI)

To reach working professionals with an interest in bioethics, the JCB has created a three-day summer institute on clinical ethics. The Clinical Ethics Summer Institute (CESI) was developed to respond to the changing needs of Canadian health care institutions. The course is intended for health care professionals, administrators, ethics committee members, ethicists, consultants and graduate students in clinical ethics who wish to learn more about the delivery of ethics services within health care settings. The program is intended to provide ethics knowledge and enhance skill development and core competencies related to clinical ethics. The institute draws on 10 years of JCB experience with ethics program development to support ethics leaders in other organizations with the ethical decision-making frameworks, practice models, tools and knowledge base to develop their own ethics programs.

Being run for the first time in 2006, the summer institute will draw on the expertise and support of the JCB Clinical Ethics Group. The themes will develop year to year based on emerging innovations, pressing needs and opportunities for skill and knowledge development in clinical ethics. The curriculum was covers a wide range of issues faced by people in the field, including:

- Building Ethics Programs
- Emerging Good Practices
- Effectiveness of Ethics Programs
- Research Ethics
- Improving End-of-Life Care,
- Priority Setting in Health Care
- Organizational Ethics Issues
- Ethical Issues involving Research and Clinical Care
- Mental Health Ethics

Endowed lectures

In addition to weekly seminars, the JCB hosts three annual endowed lectures. The Alloway Lecture Series, created in 1993, brings international experts to speak from a Judeo-Christian perspective on bioethical issues. The Jus Lecture Series, created in 1994, has a mandate to bring to the university internationally recognized major contributors to the advancement of genetics, neuroscience, psychiatry and its ethical implications. The Philippa Harris Lecture was originally established at Princess Margaret Hospital in 1981 in honour of Philippa Harris. Its aim is to raise awareness of cancer and its effect on individuals and to provide a forum to discuss bioethical issues related to cancer. See Appendix 2.
RESEARCH PROGRAMS

Interdisciplinary research is fundamental to the theory-to-practice approach of the JCB. The value of research projects is to address ethical issues, particularly those encountered in JCB partner hospitals, and to then disseminate research findings to broaden knowledge of issues, and to improve policies and practices.

In addition to the research conducted by the clinical bioethics platform, the JCB currently hosts three externally funded research networks: The Canadian Program on Genomics and Global Health, The Canadian Priority Setting Research Network and the Public Health Ethics Interest Group. Descriptions of these core research platforms are discussed in the section below.

Canadian Program on Genomics and Global Health

Global health inequity is one of the most pressing ethical challenges facing the world. Life expectancy in Canada is about 80 years and rising. In parts of the developing world, especially in Sub-Saharan Africa, partly as a result of HIV and AIDS, it is 40 years and falling. A Canadian child is likely to live twice as long as he or she would have if, by chance alone, they had been born into poverty in certain African countries.

A wide variety of factors underlie these differences in life expectancy, including issues in governance and financing, and there is no simple answer for closing the gap. But, science, technology and innovation have much to offer in diagnosing diseases, developing medicines, producing more and better foods and fighting pollution. Life sciences, including genomics and biotechnology, hold great promise in improving health and the quality of life in poorer nations. So do other emerging technologies, such as nanotechnology, which is converging with biotechnology.

"Genomics is the powerful new wave of health related life sciences (biotechnologies) energized by the human genome project and the knowledge and tools it is spawning (proteomics, transcriptomics, metabolomics, etc)"

In 2001, JCB director Peter Singer and Abdallah Daar, who directs the Program in Applied Ethics and Biotechnology, founded the Canadian Program on Genomics and Global Health (CPGGH), with the mission of harnessing genomics to improve global health equity. This was the year they published an article in Science that coined the term “genomics divide,” referring to the great disparity in ability to develop and benefit from genomics research between rich countries in the north and poorer nations in the southern hemisphere. The article, Harnessing Genomics and Biotechnology to Improve Global Health Equity, also called on the world to harness
genome-related biotechnology to improve global health equity, saying investments in this field could be used to discover new vaccines or drugs, combat HIV-AIDS and malaria, reduce pollution and improve crop yields. They proposed a five-point strategy to reduce the gap, including research, capacity strengthening, consensus building, public engagement and an investment fund. They saw this as a pragmatic approach to maximizing the benefits and minimizing the risks of genomics. An essential component of this effort is collaboration between all stakeholders including academia, industry, government and non-government organizations.

The CPGGH has strong collaborative links with scholars in other genomics, ethical, environmental, economic, legal and social issues programs of Genome Canada. Research associates and assistants, post-doctoral fellows, and graduate students help to conduct CPGGH projects. It has a 15-member international advisory board and a growing research team that already has 17 members.

Shaping the debate

The CPGGH has grown into the world’s leading program on bringing the science of genomics to improve health in the developing world. An editorial in Nature Genetics in 2001 said the CPGGH was “defining a new bioethic.” The CPGGH has developed a research methodology to address the deficiencies of current approaches to the study of the ethical, environmental, economic, legal and social implications of scientific and technological advances. This has become a world-renowned academic and policy approach to genomics and biotechnology for improving health in developing countries, and involves work as a World Health Organization Collaborating Centre.

A 2002 study done by the CPGGH and involving 28 eminent international scientists identified the Top 10 Biotechnologies for Improving Health in Developing Countries. In an article published in Nature Genetics, they called for a global initiative to share and promote the health and environmental benefits being created through genomics sciences, and thereby save tens of millions of lives each year in developing countries. The CPGGH did another report that described genomics as a global public good, and showed how the top 10 biotechnologies could promote the UN Millennium Development Goals. It proposed the creation of a global partnership, the Global Genomics Initiative, to promote genomics for health. The top 10 study was distributed to every health, industry and science ministry in the world, and was cited extensively by influential figures, including officials from developing countries. The CPGGH report also became a contribution to the ground-breaking report, Innovation: Applying Knowledge in Development, released by the United Nations in January 2005.

In December 2004, the CPGGH published a special Insight Supplement in Nature Biotechnology titled Health Biotechnology Innovation in Developing Countries. It was based on
studies of how seven innovative developing countries (Brazil, China, Cuba, Egypt, India, South Africa and South Korea), have had success in the field of genomics and biotechnology innovation. The study showed how modestly equipped research institutions were using modern genomics and biotechnology approaches to find health solutions for the poor. These included vaccines, recombinant insulin, anti-cancer agents, diagnostic tools, and other products and forms of medical knowledge. This supplement generated a large amount of international interest, and led to an article in The Economist, a discussion in the Financial Times and coverage by media outlets throughout the world.

The CPGGH has been part of the Genomics and Nanotechnology Working Group of the Science, Technology and Innovation Task Force of the UN Millennium Project. It has also been involved in research and publishing on nanotechnology and development. The article Nanotechnology and the Developing World, published by PLoS Medicine in 2005, became the most highly cited article in the journal for a period of time. This work has featured, for example, in subsequent nanotechnology legislation in Argentina.

This CPGGH methodology is also being used for a project to identify the Top 10 Regenerative Medicine Applications for the Developing World. Regenerative medicine involves research and clinical applications focused on repair, replacement or regeneration of cells, tissues or organs to restore impaired function.

Recent publications include nine papers in the International Journal of Biotechnology, on the use of knowledge for development. This includes papers on patents, publications, diasporas and brain recirculation, regenerative medicine, private sector for development, biotechnology and human security and corporate social responsibility aimed at the developing world. The CPGGH has had a major influence on public discussion of genomics through numerous press releases through national and international media outlets.

Helping to shape Canadian government policy

The CPGGH has looked at what Canada can do using biotechnology and genomics to alleviate poverty by asking three questions: What technologies are most useful for health development? What can the developing world do to harness these technologies? What can the industrialized world, and in particular Canada, do to help?

The CPGGH seeks to have a significant impact on Canada’s international science policies, and has encouraged the federal government to make a greater commitment to help transfer its knowledge on biotechnology to developing countries. In 2004, the CPGGH along with other institutions put forward ideas that led the prime minister to say that Canada had a “moral obligation” to share its medical science and research capabilities with those in need in the developing world. He stated that: “Our long-term

Prizes won by CPGGH

Work by team members at the CPGGH has led to a number of prizes:

- Singer, P.A. Dales Award, University of Toronto (2005).
- Singer, P.A. Award for Excellence, Yale University School of Public Health (2005).
- Singer, P.A. University of Toronto Department of Medicine Research Award (2006).
goal as a country should be to devote no less than five per cent of our R&D investment to a knowledge-based approach to develop assistance for less fortunate countries. Working in consultation with Canada’s National Science Adviser, the CPGGH is using evidence from research studies to develop policy options on how the government can best implement this commitment. The CPGGH is also working internationally to have this commitment adopted by other wealthy countries in an effort to reduce poverty in the developing world. The CPGGH has also worked with International Trade Canada to develop ways of encouraging and assisting commercialization of genomics and biotechnology work by Canada’s private sector in developing world markets.

Helping to shape the Grand Challenges in Global Health

Based on its reputation and the methodological expertise used to develop the Top 10 Biotechnologies paper, the CPGGH was asked to assist the Bill & Melinda Gates Foundation in its Grand Challenges in Global Health project. This $436 million US initiative of the Gates foundation, in collaboration with the Foundation for the National Institutes of Health, the Wellcome Trust, and the Canadian Institutes of Health Research, was announced in 2003. The project is a major effort to address what were identified as 14 “grand challenges” in fighting diseases that disproportionately affect the poorest 2 billion people in the world.

As a result of the work, Peter Singer has been named to the Scientific Advisory Board of the Grand Challenges Initiative. As member of the Institute Advisory Committee of the Canadian Institutes of Health Research, Abdallah Daar was able to assist Canadian and developing world scientists win three of the major Grand Challenges in Global Health grants.

In late 2005, a team of prominent bioethicists led by Peter Singer and James Lavery of St. Michael’s Hospital received a $10 million US grant from the Bill & Melinda Gates Foundation. Including Abdallah Daar, JCB member Ross Upshur and former MHSc student Jerome Singh, this grant enables the team to provide advice to the Grand Challenges in Global Health program, and to study the ethical, social and cultural issues arising out of the 43 grants awarded in the Grand Challenges program, working with ethics specialists in the developing world.

Recent work

The CPGGH is working to develop a global network on Genomics and Global Health, under the direction of JCB member Elizabeth Dowdeswell, a former UN Undersecretary General. In early 2006, the CPGGH released a report saying the world needs to ensure that global efforts to control bioterrorism do not undermine legitimate biotechnology pursuits that hold the promise of improving life for millions of the world’s poorest people. In DNA for Peace: Reconciling Biodevelopment and Biosecurity, the group called on world leaders meeting at the G8 meeting in July 2006 to create a global network of scientists and policymakers to both promote biotechnology research to fight disease, hunger and poverty, especially
in the developing world, and to keep vigil against the misuse of biological science.

The program is also working with bioscience businesses. It has studied ethical decision-making from the bioscience industry and corporate social responsibility strategies aimed at the developing world. BioIndustry Ethics, a book involving scholars from the CPGGH, Keck Graduate Institute, Université de Montréal and Stanford University and published in 2005, is the first systematic, detailed treatment of the approaches to ethical issues taken by biotech and pharmaceutical companies. It covered such issues as bioprospecting in transgenics, genomics, drug discovery and nutrigenomics, as well as how to improve stakeholder relations, design ethical clinical trials, avoid conflicts of interest and establish ethics advisory boards. The book was based on research involving 13 companies working in the life sciences, the ethical challenges they face and the mechanisms to address these.

**Funding for the CPGGH**

As principal investigators, Peter Singer and Abdallah Daar have received more than $50 million in peer-reviewed research grants in six years from leading research funding agencies in Canada and internationally, with $22 million in the past year alone. This program has raised more money than any other bioethics centre or program in the world to do empirical research on the creation, transmission and use of life sciences knowledge to help improve health in the developing world.

**Canadian Priority Setting Research Network**

Canada’s health care system is based on the principle of universal and reasonable access to medically necessary health care services. However, no health system can afford to pay for every service that people want it to provide. There are growing demands for faster access to diagnoses and treatment, as well as for home care, the provision of new medicines and illness prevention. Priority setting—deciding what health services society will provide and what will not be provided—has a direct impact on the health of individual Canadians, and is arguably the most important health system issue of this century. It involves major ethical choices affecting everyone in the country.
Priority setting occurs at all levels of the health system, from national, provincial and territorial governments to regional health authorities to hospitals and community care centres to specific clinical programs within institutions. Priority setting involves value-based decisions. In a pluralistic society, different people have different values, and often those values are in conflict. Improving priority setting can lead to a more just allocation of health resources.

Because there is no overarching principle for the just allocation of resources in the health system, key priority setting goals are legitimacy and fairness. Priority setting rationale must be publicly defensible, and decision-making must be transparent, include wide stakeholder involvement, and be subject to review and challenge. Power differences must be minimized.

The JCB seeks to be a leader in improving priority setting in the Canadian health system by developing collaborative and innovative approaches in real life cases. This work began in 1997 with a small Canadian Institutes of Health Research (CIHR) research grant to study one priority setting context, and evolved into the Canadian Priority Setting Research Network (CPSRN), a national network of scholars and decision makers.

In 2002, a $1 million, five-year grant from the Interdisciplinary Capacity Enhancement (ICE) program of the CIHR allowed an expansion of the work. The CPSRN supported the development of young and emerging investigators, including a new faculty investigator, a post-doctoral fellow and several PhD students, to conduct research in the field of priority setting. It supported studies that led to a series of papers. The CPSRN also facilitates workshops that put researchers and decision makers, including hospital administrators, provincial and federal health officials, together to share knowledge and experiences on priority setting. Presently, the network is supported by more than $3 million in grants from various sources, including the CIHR and the Alliance for Health Policy and Systems Research at the World Health Organization.

CPSRN scholars have pioneered methods to improve priority setting based on an ethical framework called ‘accountability for reasonableness’ developed by two Harvard scholars, philosopher Norman Daniels, who is arguably the world’s leading justice theorist, and James Sabin, a leading researcher in the clinical and theoretical aspects of fair resource allocation. The CPSRN has benefited from a strong collaborative relationship with Prof. Daniels, who has helped use this ethical lens to examine and improve priority setting experiences in health care organizations. CPSRN scholars have helped to refine the ethical framework through lessons learned in real life priority setting contexts. This back-and-forth exchange, improving both practice and theory, sometimes called ‘reflective equilibrium,’ has garnered CPSRN scholarship an international reputation for its high quality scholarship.

According to CPSRN’s leader, Dr. Doug Martin, the result has

The CPSRN approach to priority setting

- The goal of the CPSRN is to strengthen the Canadian health system through improved priority setting.
- We examine not only the information about priority setting, but also the institutional processes used to make decisions.
- We focus on capturing and sharing lessons derived from actual priority setting experiences.
- We complement top-down priority setting approaches by enhancing priority setting processes in institutions where it occurs, thus improving the health system from the bottom up.
been “to open up the black box of priority setting so patients and the public can see how decisions are made.” People are also gaining opportunities to contribute ideas to the process. These improvements meet a growing public demand to know about and have more say in such decisions. “These are difficult decisions about what we are going to focus on and pay for,” said Dr. Martin. “In the past, people allowed a few individuals to make these decisions behind closed doors.”

CPSRN research is based on a describe-evaluate-improve methodology developed at the JCB by Dr. Martin and Dr. Peter Singer, and guided by the ethical framework of ‘accountability for reasonableness.’ To date over two dozen research projects have focused on various priority setting contexts within the Canadian health care system, including:

- New technologies and new drugs in the context of national, provincial and hospital settings.
- Strategic planning in regional health authorities and hospitals.
- Clinical programs, such as critical care and cardiac surgery.
- A Toronto hospital’s response to SARS.

With the guidance of Dr. Jennifer Gibson, CPSRN has used its research platform to advise hospitals and health regions across the country as boards and senior management teams struggle to make resource allocation decisions based on an ethical foundation while in a difficult resource climate. In addition, CPSRN helped to shape Ontario’s practices in choosing expensive new health technologies.

Global Priority Setting Research Network

In 2003, the CPSRN provided a springboard for the launch of a Global Priority Setting Research Network (GPSRN) with a meeting among representatives of the Canadian network and 18 scholars from Chile, Ghana, India, Nigeria, Pakistan, South Africa, Uganda and Zimbabwe.

The GPSRN’s goal is to develop a long-term program of global priority setting research, building expertise and strengthening north-south collaborations in global health research. Its aim is to share priority setting lessons in a way that will provide guidance to decision makers struggling to make crucial priority setting decisions, and improve priority setting in health care institutions around the world.

Through the guidance of Dr. Lydia Kapiriri, Research Associate, the GPSRN has conducted case studies of priority setting in institutions in Africa, South Asia and Latin America. This
represents the first global comparison at the institutional level of how resource allocation decisions are made using a common ethical framework ‘accountability for reasonableness’. In addition, the GPSRN has facilitated four regional workshops in Africa to share knowledge and experiences, and to help decision makers improve their priority setting practices. In 2005, the GPSRN began collaboration with Dr. Fernando Lolas, head of the Pan American Health Organization bioethics unit based at the University of Chile, to develop a program of research and capacity building in regard to priority setting across Latin America.

In September 2006, the CPSRN and the GPSRN will host the prestigious 6th International Conference on Priorities in Health Care in Toronto. This meeting will bring together an international group of health professionals, administrators, economists, policy makers, philosophers, ethicists and scholars from over 80 countries. The conference theme is Real World Priority Setting, and the goal is to share experiences and improve priority setting worldwide.

Public health ethics interest group

“Ten years ago, no one cared about public health ethics,” recalls Ross Upshur, a founding member of the public health ethics interest group. Then came a series of public health crises. First was the tainted blood scandal and the Krever Commission report on the issue in 1997. In 2000, there was contamination of the water supply for Walkerton, Ontario. Next was the SARS (Severe Acute Respiratory Syndrome) health crisis of 2003. These triggered a wave of interest in the ethics of decisions affecting public health.

In 2000, a group of scholars affiliated with the JCB started the public health ethics interest group, a network of scholars that has evolved into a research and education program.

By 2001, the group had identified four key public health themes:

1. Surveillance and regulation. What are the ethical implications of genetic screening and the storage of resulting information in electronic databases?

2. Individual rights compared to collective (social) rights. How can coercion of individuals for public health goals be justified? How should the rights of the individual be balanced against community rights?

3. Risk and precaution (including environmental issues). What are the ethical implications of the precautionary principle, which was developed to deal with environmental risks, for public health ethics? How can people best balance the need for greater scientific (causal) knowledge with the need to take action to protect the health of populations?

4. Social justice and equity (including global issues). What is the relationship between public health and social justice? What are the ethical implications of widening economic disparities and global public health?

By 2002, the group hosted an International Symposium on Public Health Ethics, and Ann Robertson and Ross Upshur created the first graduate level course in Canada on public health ethics.
The ethics group has tackled a number of issues. Members are actively researching ethical aspects of vaccination programs, such as who should have to be vaccinated, non-medical exemptions to vaccines, surveillance of the side effects of vaccines and no fault compensation schemes for vaccine harm. They have researched health information privacy in such areas as genetic databases, and have collaborated in the first textbook on public health ethics and law. They have a proposal to increase training on public health ethics at the doctoral and post-doctoral levels.

Some of the most publicly visible work has been around the ethical implications of major disease outbreaks. The threat to public health from SARS forced decision makers to balance individual freedoms against the common good, fear for personal safety against the duty to treat the sick, and economic losses against the need to contain the spread of a deadly disease.

A group of nine JCB scholars analyzed the way the SARS outbreak was handled from an ethical perspective, particularly in Toronto hospitals. The study identified 10 key ethical values and five major ethical issues in the SARS incident. They found that leaders in governments and health care systems were not prepared with an ethical framework, and had not held prior consultations on how to deal with the range of ethical issues forced on them by SARS. Decisions had to be rapid, and were as transparent as possible given the limitations of the time. A key lesson is to establish an ethical framework in advance of a public health crisis, and to do it in a transparent manner.

Following the 2003 outbreak, the group wrote an important paper published in the British Medical Journal on findings of their research, and submitted a brief to the Naylor Commission on how SARS was handled in Canada.

One of the most pressing questions in dealing with a public health crisis involves the duty of health care workers to provide care at a risk to their own health. The team researched difficult and very personal questions about the amount of danger a health care worker is morally obliged to face. There are also questions of how health systems can be designed to minimize risks to health care workers, particularly in the case of diseases that are very difficult to treat. The JCB has been asked to advise Canada’s medical associations.

The work on SARS forged strong links between the work of the public health ethics and priority setting groups at JCB, and identified good practices and opportunities for improvements in handling ethical issues in the case of future disease outbreaks.

More recently, the spread of avian influenza raised the risk of a possible global influenza pandemic on the scale of the 1918 outbreak that killed millions. Health experts say the world is due for another major influenza pandemic that could sicken or kill millions of people around the world. The same ethical issues that arose

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**Five major ethical issues that were faced by decision makers during the SARS crisis**

- Health care workers’ duty to care and the duty of institutions to support them.
- The ethics of quarantines. When does public health trump civil liberties?
- Naming names and communities. How to balance privacy of personal information and public need to know.
- Restricting medical care for many by limiting hospital access in order to control the spread of the disease.
- Making decisions in a world in which diseases can move around the planet in hours and information about them is broadcast globally in minutes.
during the SARS outbreak will arise, but with a vengeance, in an influenza pandemic. Anticipating the consequences of a pandemic, the JCB formed a team of experts to look at the lessons from SARS.

It created the Pandemic Influenza Working Group to make recommendations on ethical decision-making in the face of this threat. This working group evolved through the collaboration of several JCB platforms beginning with clinical ethics and expanding to organizational ethics, priority setting and public health. The group said that if there were a pandemic, health care workers would face exposure to a disease for which there would be no absolute protection or cure. They would face competing demands to care for patients and to protect their health and that of families and friends.

There would also be decisions about allocation of scarce medical care and the imposition of restrictive measures, such as quarantines, which would limit individual rights in order to protect the common good. People would be cut off from family, friends, work, jobs and even food. They would at least need care and job protection.

In late 2005, the group said that shared ethical values are the glue that holds a society together during an intense crisis, and recommended that pandemic plans being developed around the world be founded on commonly held ethical values. They said the SARS experience shows that people are more likely to accept rules for dealing with a pandemic if the decision-making processes used to set such rules were reasonable, open and transparent, inclusive, responsive and accountable, and if reciprocal obligations are respected. The report that emerged from this work stated:

“Government and health care leaders need to make the values behind their decisions public. They should discuss the values with people who could be affected, ranging from health care workers, who will find themselves on the front lines, to government officials, who are making decisions about the allocation of limited resources, to the public at large, because people will be affected in many ways. They need to do this in advance of a health crisis, not when people are lining up at emergency ward doors.”

The group said that pandemic planners had been focussing on the technical issues of medicines and duties, but had not generally communicated the ethical underpinnings of their choices in a clear manner.

They identified four major ethical issues that need to be dealt with in pandemic plans:

- Health workers’ duty to provide care during a communicable disease outbreak.
- Restricting liberty in the interest of public health with measures such as quarantines.
- Priority setting, including the allocation of scarce resources, such as vaccines and antiviral medicines.
- Global governance implications, such as travel advisories.

Public Health Ethics – Main Funders
1. Canadian Institute of Health Research
2. Connaught Fund
3. Joint Centre for Bioethics
The group also cited 10 substantive values to guide ethical decision making for a pandemic:

- Individual liberty
- Protection from public harm
- Proportionality
- Privacy
- Duty to provide care
- Reciprocity
- Equity
- Trust
- Solidarity
- Stewardship

**Five procedural values to guide ethical decision-making for a pandemic influenza outbreak**

1. **Reasonable**
   Decisions should be based on reasons (i.e., evidence, principles, and values) that stakeholders can agree are relevant to meeting health needs in a pandemic influenza crisis. The decisions should be made by people who are credible and accountable.

2. **Open and transparent**
   The process by which decisions are made must be open to scrutiny, and the basis upon which decisions are made should be publicly accessible.

3. **Inclusive**
   Decisions should be made explicitly with stakeholder views in mind, and there should be opportunities to engage stakeholders in the decision-making process.

4. **Responsive**
   There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis. There should be mechanisms to address disputes and complaints.

5. **Accountable**
   There should be mechanisms in place to ensure that decision makers are answerable for their actions and inactions. Defence of actions and inactions should be grounded in the 14 other ethical values proposed above.

In fact, the advice of the JCB has influenced ethical components of some influenza pandemic plans, such as those for Ontario, Toronto and for the city’s hospitals. The group’s work has been presented to the U.S. Centres for Disease Control, the World Health Organization and the Public Health Agency of Canada, as well as other universities, health care organizations and conferences internationally.
PUBLIC OUTREACH

The JCB aims to serve as a public resource to the community and the media.

The JCB has had a major influence on public discussions on the ethical, environmental, legal and social implications of health care development through a variety of approaches, ranging from publications to media to theatre.

It puts a great effort into building expertise in the health care field, in influencing medical policies, and developing research and academic publications in important areas. The organization also makes a strong effort to inform the public about bioethics, and to engage people in thinking about and discussing these issues. The goal is to promote a broader and better understanding of bioethics issues. It has developed a series of approaches to communicate its research and advice, using academic journals, the news media, the Internet, education tools, theatre and speakers. Key pieces of work are turned into papers used to inform broader audiences, including leaders in the health care field and governments that make health care decisions.

For example, in early 2006, the JCB issued a paper calling for world leaders to ensure that efforts to prevent bioterrorism do not undermine legitimate efforts to use biotechnology to improve health and living conditions in developing countries. In these and similar high-profile cases, the JCB has a practice of producing versions of its work that are meant to inform the non-scientist. It uses specialists to see that the information is transmitted to the public through the news media. As a result, hundreds of stories have been carried about JCB findings and advice, not only in Canada but internationally.

It has worked with others to develop teaching modules to help students understand the complex ethical decisions that arise in health care. It collaborated in the development of a play to educate the public about the issue of genetic testing, and to engage people in discussions as a way of helping to inform the development of health policy with values held by members of the public.

Public engagement technologies

The JCB has adopted advanced technologies as a major new way to communicate with and engage a wide range of audiences in discussions of bioethics. For years, its website has been a major international resource on bioethics, providing an online library containing an extensive array of materials, open to anyone in the world with access to the web.

The JCB is a partner in a project with the Centre for Global eHealth Innovation of the University Health Network to use new technologies to further teaching and to engage stakeholder groups and the general public in issues of health policy, services, and governance. Funding has come from the participating organizations and from the Canada Foundation for
Innovation, Ontario Innovation Trust and the Charles E. Frosst Foundation for Healthcare.

Project manager Laura Heller said the project, seeks not just to communicate, but also “to get feedback on a lot of important issues.” Various technologies are being used, including voice connections and text messaging. Handheld devices are being used to let people respond to speakers on the spot in what amounts to a form of continuous polling as ideas are being presented.

She said public engagement involved getting responses on policies and priority setting, responses on how the health care system is doing and research in which people are asked to provide information on various issues, which could include disease outbreaks and adverse drug reactions. “It becomes a powerful tool for public education and public engagement. It allows the public to become active participants in bioethics debates. It helps in making hard decisions on how we remake our health care system.”

Even before the final installation of equipment in 2006, there were signs of success. For example, she said, lectures that normally drew 30 people to hear world experts were being webcast to hundreds of people. In six months, more than 3,000 people had visited the website to listen to and see the lectures online. “The potential for learning and professional development is greatly extended,” she added.

Newer forms of Internet technology known as webcasting allow even more personal connections via computers. Presentations are broadcast live to the Internet, and the live events are stored so that people can see and hear the speakers at any time through an electronic archive. The JCB is working to use two-way technology that allows people far away to pose questions to speakers and hear the responses, using videoconferencing and online seminars.

**Project Engage**

The JCB reached out to high school students with a project to have them learn about and debate a difficult ethical issue, the use of human stem cells to deal with diseases currently incurable by conventional approaches.

*ENGAGE: Stem Cells* is a high school teaching resource that has teenagers play the roles of key stakeholders, including lawmakers, scientists, industry, health organizations and representatives of different religions. It challenges them to draft legislation to govern medical research using embryonic stem cells. The teaching module was developed using materials prepared by the JCB and the Ontario Genomics Institute, with support from Genome Canada and the Stem Cell Network. It drew support from a number of other institutions.

Erin Court, who went on to study bioethics, was a just-graduated high school student who helped develop the stem cell module, starting in 2001. At the time, Parliament was debating stem cell legislation, and the project sought to get high school students to have their own debate so they could better understand the difficult ethical choices in such an issue. She recalls a teacher saying that some of the student views were better informed than those of some MPs.
Since 2003, the teaching module has been sent to 4,000 high schools across Canada, and is being used as a model by other countries. It also led to a similar project on nanotechnology.

**Theatre**

Theatre has a long history of engaging the public in moral, social, and political issues. Physician and playwright Jeff Nisker is using it as a public engagement tool for health-policy development, particularly in the fields of reproductive and genetic technologies.

Dr. Nisker, JCB member and Coordinator of Health Ethics and Humanities at the Schulich School Medicine, University of Western Ontario, received support from the Canadian Institutes of Health Research grants, and worked in collaboration with the JCB to write two plays that seek to engage people in the complex issues around genomics. *Sarah's Daughters* is the story of a young woman living in fear of hereditary breast cancer for which there is a genetic test that indicates a risk. It was performed for some 1,400 people in 12 locations across Canada, in 2002. *Orchids* deals with the ethics of genetic selection in artificial conception. It was performed in Toronto, Vancouver and Montreal for the general public (followed by workshops) and in invited venues, often as part of conferences, in 2005. Audiences include the general public, health-care providers, policy makers, educators, students and scholars.

The plays are used to educate people about the scientific, clinical and psychosocial issues regarding genetic testing, and to trigger audience discussion. People are invited to stay after the play and provide responses. The result is both engagement and research about how people feel about these sensitive and complex issues. Dr. Nisker said that audience members offered informed and diverse opinions on policy issues, including resource allocation, patenting of genetic tests, research funding, genetic test-based insurance discrimination and the need for public education on these issues. Dr. Nisker is using the audience reaction to the presentations as a gauge of how people feel about these subjects. These “give us a sounding of public and expert opinions on complex health issues.”

A graduate of the JCB Collaborative Program in Bioethics, Dr. Nisker was co-chair of Health Canada’s Advisory Committee on Reproductive and Genetic Technology. Health Canada is using the theatre approach as a way of informing its policies on genetic testing.

**Media coverage**

As part of its mission of informing and engaging the public on complex ethical issues, the JCB communicates extensively through the news media, not just in Canada, but also at a global level. This includes written print, television and radio interviews. They’re “punching above their weight,” said media consultant Terry Collins, who has worked extensively with the JCB.

He noted that JCB stories have received extensive coverage in Canadian news media. In addition, JCB director Peter Singer regularly has access to space to write extended commentary articles on key issues.
The JCB has also been covered by global news service such as Reuters and Associated Press, which reach all of the world's some 15,000 newsrooms. He said it is not unusual to see 200 news stories from Canada and overseas arising from one JCB report. Mr. Collins said that there is interest among journalists from developing world media because of the JCB's international work. For example, Spanish language journalists working in Canada will file stories about the JCB to Mexico and Spain.

Such reports as the *Top 10 Biotechnologies for Improving Health in Developing Countries*, pandemic flu and the Top 10 Ethical challenges as well as the later study of how developing countries were making use of biotechnology received extensive international coverage by the media.

"In the media, the JCB is far more visible than anybody else in the field," he added. The organization gets coverage in such major outlets as the *Times of London, BBC, Xinhua News of China, Kyodo News of Japan, The Economist and New Scientist Magazine*. 
APPENDIX 1
THE JCB PEOPLE

BOARD OF DIRECTORS
The University of Toronto Joint Centre for Bioethics (JCB) is governed by a Board consisting of the CEOs (or designates) of the participating hospitals and the Deans (or designates) of the relevant university faculties. The chair of the board is the University of Toronto's Vice-Provost Relations with Health Care Institutions.

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**CLINICAL ETHICS FELLOWS**

2001-02

Paula Chidwick
Laurie Hardingham

2002-03

Dianne Godkin
Karen Faith
Laurie Hardingham (Senior Fellow)

2003-04

Jonathan Breslin
Alisa Swota
Shawn Winsor

2004-05

Eoin Connolly
Jonathan Breslin (Senior Fellow)
James Hynds
Sharon Reynolds
Heather Sampson
Alison Thompson

2005-06

Kyle Anstey
Halley Faust
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James Hynds (Senior Fellow)
Suzanne Manning
Deborah Pape
Sharon Reynolds (Senior Fellow)
Julie Skeldon
Adrian Viens (special book project)

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Shawn Tracy  
Kumanan Wilson  

**Pandemic Influenza Working Group**  
Karen Faith  
Alison Thompson  
Jennifer Gibson  
Ross Upshur  
Peter Singer  
Kumanan Wilson  

**SARS**  
Solomon Benatar  
Mark Bernstein  
Abdullah Daar  
Bernard Dickens  
Ross Upshur  
Linda Wright  
Sue MacRae  
Randi Zlotnik Shaul  
Peter Singer  

**COLLABORATIVE PROGRAM IN BIOETHICS (CPB)**  
*Graduated Students listed by year of degree awarded*  

**Students currently enrolled in CPB**  
Marian Adly  
Victor Cellarius  
Eoin Connolly  
Heather Gordon  
Rebecca Greenberg  
Tara Hannah  
Lisa Hicks  
Christine Houston  
Anita Huntley  
Pamela Kolopack  
Kuei-hsun Liao  
Shannon Madden  
Barry Pakes
Zahava Rosenberg-Yunger
Heather Sampson
Rob Sibbald
Diego Silva
A Erica Sutton
Anne Simmonds
Catherine Tansey

**Degrees to be awarded in 2006**
Victor Cellarius
Barbara Ellen Gibson
Stephanie Nixon
David Reeleder
Rob Sibbald

**Degrees awarded in 2005**
Jeff Nisker
Andrew Taylor
Alison Thompson
Sarah Urowich
Nancy Walton

**Degrees awarded in 2004**
Jocelyn Mackie
Marion Motari
Julie Spence

**Degrees awarded in 2003**
Kathy Carlin
Shannon Madden
Marion Motari
Phillip Karpowicz
Daniel Sperling

**Degrees awarded in 2002**
Pierre Coté
Jennifer Gibson
Eszter Kismodi
Shawn Richard
Sara Rosenthal
Leslie Soever
Pamela Spencer

**Degrees awarded in 2001**
Alina Gildiner
Elaine McIlroy
Matt Mokanski
Benoit Morin
Barbara Secker

**Degrees awarded in 2000**
Marianna Gorbataia
Paul Miller
Tara Stadius
Randi Zlotnik Shaul

**Degrees awarded in 1999**
Eve DeVaro
Karen Faith
Laura Hawryluk
Josh Kline
Jim Lavery
Dany Merkel
Merril Pauls
Sharad Rai
Sergio Rueda
Louise Sanchez-Sweatman

**Degrees awarded in 1998**
Gordon DuVal
Barbara Gibson
Sara Rosenthal
Stephen Workman
Deborah Zinman

**Degrees awarded in 1997**
Diana Barrigar
Sharon (Rea) Ikonomidis
David Kaplan
Elizabeth Peter
Natasha Sharpe

**Degrees awarded in 1996**
Kerry Bowman
Doug Martin
Shirley Netten

**Degrees awarded in 1995**
Michelle Mullen

**Degrees awarded in 1994**
Kathy Carlin
Nancy Ondrusek

**Degrees awarded in 1993**
Nitsa Kohut
Jim Lavery
Hussein Noorani
Sharon Rea
Alison Williams
Linda Young

**Degrees awarded in 1992**
Mehran Sam
Randi Zlotnik Shaul
MHSC IN BIOETHICS

Domestic and International Students

Class of 2006 – International
Ayodele Jegaede
Tarf Bakdash

Class of 2005 Domestic
Kevin Coughlin
Dorothyann Curran
Mark Handelman
Maria McDonald
Bob Parke
Barry Schwartz

Class of 2005 – International
Adebayo Adejumo
Anant Bhan
Mina Majd

Class of 2004 – Domestic
Andrew Cooper
David Gerber
Sylvia Hyland
Renata Leong
Patrick McDonald
Sharon Reynolds
Jim Rusthoven
Heather Sampson

Class of 2004 – International
Sunita Bandewar
Robyna Khan
Mohanam Nair
Temidayo Ogundiran
Jagdishwar Srivastava
Paulina Tindana

Class of 2003 – Domestic
Mark Bernstein
Tania DePellegrin
Pierre LaPlante
Elyse Levinsky
Doreen Ouellet
Shawn Winsor

Class of 2003 – International
Aasim Ahmad
Eric Amuah
Nalin Mehta
Busi Nkala
Jerome Singh

Class of 2002 – Domestic
Joan Bevan
Monica Branigan

Annie Fecteau
Monique Fourcaudot
Mark Lachmann
Larry Reynolds
Heather Ross
Doreen Rushbrook
Jackie Smith
Linda Wright
Joel Yaphe
Kin Fan Young Tai

Class of 2002 – International
Marcela Ferrer
Nandini Kumar
Jens Mielke
Joseph Ochieng
Asad Raja
Dhanapal Ravindran

Class of 2001 – Domestic
Scott Berry
Jeff Blackmer
Sara Davison
Alex Levin
Aideen Moore
Susan Pilon
Jodi Shapiro
Ellen Tsai

Class of 2001 – International
Aasm Ahmad
Erc Amuah
Nalin Mehta
Busi Nkala
Jerome Singh

ADMINISTRATIVE STAFF
Carmen Alfred ^^
Laurie Bulchak
Gillian Bentley
Connie Carrozzi ^^
Emma Culpeper
Carolyn Farrell ^^
Adrienne Grapko ^^
Chris Joseph
Brenda Knowles ^^
Agnieszka Kowalski
Rhonda Martin ^^
Carol Nash
Margot Smith
Ada Wong

^^ Current Staff

CONSULTANTS
David Brook
Terry Collins
Laura Heller
Michael Keating
Eugene Vesely
David Watters
APPENDIX 2
ANNUAL LECTURES

ALLOWAY LECTURE

The purpose of the Alloway Lecture Series, established by the Maranatha Foundation in 1993, is to bring to the university each year one or more experts of international stature in the field of bioethics. They are to deliver lectures on topics related to ethical aspects of organ transplantation, when possible, but the lectures are not limited to this field of medical ethics.

Criteria:
• The speaker has international stature.
• The speaker has made important contributions to the general field of bioethics and hopefully, but not necessarily, to the field of organ transplantation, including its ethical aspects.
• The speaker’s work is relevant to the objectives of the jcb.
• The speaker’s approach to bioethical issues is foundationally based on established Judeo-Christian principles.

PREVIOUS SPEAKERS:

2005
Vanessa Northingham Gamble
Where’s race in bioethics?

2004
James Tulsky
Going gently into the good night: defining and improving quality at the end of life

2002
Leon R. Kass
Why not immortality

2001
Edmund Pellegrino
Do patients and physicians need bioethics

1999
Julia Neuberger
Being reasonable about rationing - making tough decisions

1998
James Childress
The failure to give: ethical barriers to obtaining organs for transplantation

1997
Daniel Sulmasy
Adam Smith at the bedside: should health care be considered a market commodity?

1996
Patricia Benner
The compassionate stranger: exploring caring practices and the ethics of care

1995
Mark Siegler
Clinical ethics: its contribution to patient care

1994
E. David Cook
Medical moral mazes: theological perspectives

1993
Daniel Callahan
Ethics and the medical ambivalence toward death

COMMITTEE MEMBERS:

Peter Singer (Chair)
Sue MacRae
Miller Alloway Jr.
Robert R. Alloway
Mark Henkelman
Robert D. Inman
Mark Henkelman
J.F Kennedy, QC
Hazel Markwell
Carmen Alfred
**JUS LECTURE**

The Jus Lecture Series was created by Dr. Karolina Jus in 1994 in honour of her late husband, Dr. Andrzej Jus. Its mandate is to bring to the University of Toronto an internationally recognized major contributor to the advancement of genetics, neuroscience, psychiatry and its ethical implications.

PREVIOUS SPEAKERS:

- **2006**
  - Mohamed Hassan
  - *Promoting a Culture of Excellence in Scientific Research and Education in Developing Countries*

- **2004**
  - Michael Gazzaniga
  - *Simple and Complex Issues in Neuroethics*

- **2003**
  - Zach Hall
  - *Neuroethics: A challenge for a new age*

- **2002**
  - John Bell
  - *Genetic risk factors: the ethical dimensions*

- **2000**
  - Michael Marrus
  - *Invoking the Nazis in bioethics*

- **1999**
  - James Watson
  - *DNA and politics*

- **1998**
  - Floyd Bloom
  - *Basically honest is not good enough in science*

- **1997**
  - Fred Gage
  - *Gene and cell transfer to the brain: science and ethics*

- **1996**
  - Anne Young
  - *Scientific and ethical dilemmas of advances in Huntington’s disease*

- **1995**
  - Jean-Pierre Changeux
  - *Reflection of a neuroscientist on the foundations of ethics*

**COMMITTEE MEMBERS:**

- Peter Singer (Chair)
- Sue MacRae
- Peter St. George-Hyslop
- Mary Seeman
- James Sharpe

**HARRIS LECTURE**

The Harris Lecture was established at Princess Margaret Hospital in 1981 in memory of Philippa Susan Louise Harris, who died from cancer at Princess Margaret Hospital over two decades ago. Philippa, as she was known to her family and friends, was a compassionate young woman, curious and scholarly. For the past two decades, Bill and Pat Harris have sponsored this lecture as an opportunity to raise awareness of cancer and its effect on individuals and to provide a forum to discuss bioethical issues related to cancer.

PREVIOUS SPEAKERS:

- **2005**
  - Bartha Knoppers
  - *Bench to Bedside: The Ethics of Emerging Professional Duties in Oncology*

- **2004**
  - Monca Brangan
  - *Terminal Sedation*

  - Edward Etchells
  - *Leaving the Burning Platform: Ethical Issues in Patient Safety*

- **2003**
  - Ezekiel Emanuel
  - *The Ethics of Phase I Oncology Research*

- **2002**
  - Derek Yach
  - *Genomics, cancer and other noncommunicable diseases: a global health perspective*

- **2001**
  - Panel on Ethics and Cancer

  - Scott Berry
  - *Advance care planning for people with cancer.*

  - Larissa McWhinney
  - *Esophagactomy for cancer: trusting the doctor.*

  - David D’Souza
  - *The waiting list for radiotherapy: a case study.*

  - Doug Martin
  - *Priority setting for new cancer drugs.*

  - **MODERATORS:**
    - John Evans
    - David Smith

- **2000**
  - Norman Daniels
  - *Limits to health care: making decisions accountable for reasonableness*
1999
Joanne Lynn
*When all is said and done – improving end of life care*

1998
Kathleen Foley
*Transforming the culture of death*

1997
Barrie Cassileth
*Alternative and complementary medicine: problems and promises*

1996
Nuala Kenny
*Ethical issues in the face of suffering*

1995
Rob Buckman
*Truth, hope and information*

1994
Margaret Somerville
*Assisted suicide and Sue Rodriguez*

1993
Susan Sherwin
*Feminism ethics and health care*

1992
Janet Storch
*Ethics in a time of shrinking resources*

1991
E.J. Latimer
*Nobility, dignity, humanity - ethical care of the dying with reflections on euthanasia*

1990
Eric Cassell
*Hope as an enemy*

1989
Renee Fox
*Training in caring competence: the perennial problem in North American medical education*

1988
Jay Katz
*Duty and caring*

1987
Abbyann Lynch
*Managing ethical differences - the role of patient and practitioner*

1986
John Bowker
*Is your dying really necessary?*

1985
Robert Veatch
*Quality of life – the ethics that we choose in therapeutic decision making*

1984
Milton Rokeach
*The nature of human values and the role in the psychosocial care of cancer patients*

1983
Arthur Schmale
*Evaluating the psychosocial needs of patients with cancer*

1982
Wendy Schain
*Sexuality, sex therapy and cancer care*

1981
Avery Weisman
*The caregiver’s plight*

**COMMITTEE MEMBERS:**

Andrea Bezjak
Karen Gaymen
Greg Lichti
Sue MacRae
Linda Wright
Carmen Alfred
APPENDIX 3
PUBLICATIONS 1995–2005


Lemmens T, Miller PB. Balancing ethical research issues in psychiatry. Psychiatric Times 2000 (June): 63-7

Martin DK., Emanuel LL., Singer PA. Planning for the End of Life Lancet 2000; 356: 1672-76

McNeeley MF. Ethical problems in surgery: innovation leading to unforeseen consequences. World J of Surgery 1999; 23: 786-8


Singer PA., Martin DK, Giacomini M., Purdy L. Priority setting for new technologies in medicine: qualitative case study BMJ 2000;321:1316-1318


Benatar SR. The coming catastrophe in international health: an analogy with lung cancer. International Journal 2001; LVI (4) 611-31


Benatar SR. We must broaden the scope of research ethics. SciDev.Net November 1, 2002


Bernstein M, Bampoe J. Surgical innovation or surgical evolution: an ethical and practical guide to handling novel neurological procedures. Journal of Neurosurgery 2003; 100 : 2 - 7


Bernstein M. (under the pseudonym of Hari Gunkwell). A radical solution to the Middle East conflict – If no peace, then separaton? Canadian Muslim News 2003; September 17.

Bernstein M. A bad joke. The Ottawa Citizen, May 14, 2003; A17.


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Dickens BM. Can Science or Ethics Compromise Each Other in Human Subject Research? in *Science and Ethics, P Demers (ed.), Toronto: Royal Society of Canada, University of Toronto Press 2001; pp3-23.


Gordon M. Beyond the Hippocratic Oath: ethical challenges in the care of elders.” Journal of Geriatric Care 2002; 12(1)

Gordon M. Cardiopulmonary resuscitation in the elderly: If we could provide it should we? Humane Medicine 1995; 11: 96-7.


Gordon M. CPR in Long-Term Care: Mythical Benefits or Necessary Ritual? Annals of Long-Term Care 2003; 11(4): 41-49.

Gordon M. Does cross-border prescribing threaten the greater good? The Medical Post 20 April 2004; 11.


Gordon M. In Long-Term Care, the “R” in CPR is not for Resurrection. Annals of the Royal College of Physicians and Surgeons of Canada 2001; 34: 441-443.


Gordon M. Martin ‘states opinions as facts’ in Medicare article. [Letter to the Editor]. Canadian Medical Post 8 August, 2000, p. 17.


Gordon M. Paid to prescribe: Are physicians who accept payment for pushing certain drugs trading in their professionalism? The Medical Post 26 August 2003; p. 11.


Gordon M. Resuscitation policies in long-term care institutions. Geriatrics and Aging 2001; 4(1); 22-23.

Gordon M. SARS, terrorism and the media. The Medical Post 2003; July 29, p. 3.


Gordon M. Should we conduct research on persons with dementia? Geriatrics and Aging 2001; 4(3).


Gordon M. When George met Gladys: who decided when long-term care patients should have romantic or sexual relationships? The Medical Post February 17 2004; p. 13.
Harrison C. Hilliard P. Postgraduate Pediatric Residents’ Perceptions of Ethical Dilemmas
Hicks LJ, Lin Y, Robertson DW, Robinson DL, Woodrow SJ. “Understanding the clinical dilemmas that shape medical students’ ethical development: questionnaire survey and focus group study”. BMJ 2001;322:709-710
Hoffman BF. Importance and Limits of Medical Confidentiality. Health Law in Canada 1997; 17: 93-5.
Invited Presentation: Bernstein M. Plenary session talk at Canadian Congress of Neurological Sciences Meeting in Calgary, June 8 - 12, 2004 on “Error and Patient Safety”


Kozer E, Scolnik D, Keays T, Shi K, Luk T, Koren G

Kohut N, Sam M, O’Rourke K, MacFadden DK, Salit I, Singer PA

Kodish E, Singer PA, Siegler M

Koch T, Rowell M

Knox-Macaulay H, Ayyaril M, Nusrat N, Daar AS.


Kozer E, Scolnik D, Keays T, Shi K, Luk T, Koren G

Kohut N, Sam M, O’Rourke K, MacFadden DK, Salit I, Singer PA

Kodish E, Singer PA, Siegler M

Koch T, Rowell M


Lemmens T. SARS is bad. Malaria is worse. The National Post 2003; May 2.


Lemmens T, “Reading the Book of Life: now that we have a partial script for human genes, who should read it—and how should it be sold?” University of Toronto Bulletin 2000; 16.


Levin AV. IOLs, Innovation, and Ethics in Pediatric Ophthalmology. Journal of AAPOS 2002; pp133-135


Martin DK, Abelson J, Singer PA. Participation in health care priority setting through the eyes of the participants. Journal of Health Services Research and Policy 2002; 7:222-229


McKneally MF. Bioethics of the Refusal of Blood by Jehovah’s Witnesses: Part 3. A Proposal for a Don’t Ask—Don’t Tell Policy. CT Digest http://ctdigest.com/Feb00/Feb00.html#rev=4 (on-line publication)


McKneally MF. Slippery Slopes in Flat Countries – A Response. CT Digest ctdigest.com/May99/May99.html#rev=4 (on-line publication)

McKneally MF. The Role of Ethical Principles in Health Care and the Implications for Ethical Codes. CT Digest ctdigest.com/Dec99/Dec99.html#rev=5 (on-line publication)


Morin B. “The Fiction of Bioethics: Cases as Literary Texts” by T. Chambers Book review, Philosophy in Review, 2000; 20(1)


### APPENDIX 4
### GRANTS HELD AT THE JCB 1995–2005

<table>
<thead>
<tr>
<th>Scott</th>
<th>Berry</th>
<th>The Acceptability of a Cancer Specific Living Will in Oncology</th>
<th>The Physicians' Services Incorporated Foundation (PSI)</th>
<th>1995-96</th>
<th>14,856</th>
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<tr>
<td>Kerry</td>
<td>Bowman</td>
<td>Chinese seniors’ attitudes towards advance directives</td>
<td>Chinese seniors’ attitudes towards advance directives</td>
<td>1995-96</td>
<td>25,075</td>
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<td>Sujit</td>
<td>Choudhry</td>
<td>Recasting Social Canada: A Reconsideration of Federal Jurisdiction over Social Policy</td>
<td>Cecil M. Wright Foundation</td>
<td>2000</td>
<td>5,000</td>
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<tr>
<td>Sujit</td>
<td>Choudhry</td>
<td>Recasting Social Canada: A Reconsideration of Federal Jurisdiction over Social Policy</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC) New Investigator Award</td>
<td>2000</td>
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<tr>
<td>Abdallah Daar (Co-Applicant)</td>
<td></td>
<td>Representation of genomics research among Latin American Laymen and Bioethicists</td>
<td>US Department of Energy (US$250,000 @ 1.33)</td>
<td>2003-05</td>
<td>332,500</td>
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<tr>
<td>Abdallah Daar (Co-Applicant)</td>
<td></td>
<td>Training Program in Regenerative Medicine</td>
<td>Canadian Institutes for Health Research</td>
<td>2002-07</td>
<td>1,500,000</td>
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<tr>
<td>Abdallah Daar (Co-Applicant)</td>
<td></td>
<td>Regenerative and Nanomedicine Partnership Program - NET Program: Regenerative Medicine</td>
<td>Canadian Institutes for Health Research</td>
<td>2004-09</td>
<td>1,500,000</td>
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<tr>
<td>Abdallah Daar</td>
<td></td>
<td>Genomics and Global Health: Developing a Global CIHR Network to Address Ethical, Policy, and Regulatory Issues</td>
<td>Canadian Institutes for Health Research</td>
<td>2003-04</td>
<td>62,700</td>
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<td>Abdallah Daar</td>
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<td>Legal Modes of biotechnological intellectual property protection: a transdisciplinary approach</td>
<td>McGill University</td>
<td>2004-05</td>
<td>33,600</td>
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<td>Abdallah Daar (Co-Investigator)</td>
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<td>Legal models of biotechnological intellectual property protection: A transdisciplinary approach</td>
<td>Social Sciences and Humanities Research Council of Canada, Initiative on the New Economy, Collaborative Research Initiative</td>
<td>2003-07</td>
<td>2,989,500</td>
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<td>Raisa Deber</td>
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<td>Preferences for Participation in Medical Treatment Decisions</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC)</td>
<td>1997-99</td>
<td>78,600</td>
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<td>Raisa Deber</td>
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<td>The impact of population-based funding on specialized services</td>
<td>Medical Research Council (MRC)</td>
<td>1998-99</td>
<td>65,204</td>
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<td>Gordon DuVal</td>
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<td>Ethics of Drug Treatment Research</td>
<td>Canadian Institutes of Health Research: INMHA</td>
<td>2003-04</td>
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<td>Gordon DuVal</td>
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<td>Consent to Drug Treatment Research: A Pilot Qualitative Study</td>
<td>Associated Medical Services, Inc.</td>
<td>2004-05</td>
<td>24,355</td>
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<td>Title</td>
<td>Funding</td>
<td>Group/Institution</td>
<td>Year</td>
<td>Amount</td>
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<td>Ed Etchells</td>
<td>Evaluation of Questionnaires and Decisional Aids to Consent to Life-Sustaining Treatment</td>
<td>The Physicians' Services Incorporated Foundation (PSI)</td>
<td>1994-96</td>
<td>116,540</td>
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<td>Evaluation of the 'Aid to Disclosure Evaluation' (ADE)</td>
<td>The Physicians' Services Incorporated Foundation (PSI)</td>
<td>1997-99</td>
<td>123,000</td>
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<td>Michele Ferrari</td>
<td>Developing Ethics Expertise Using Case Histories of Informed Consent</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC)</td>
<td>1999-02</td>
<td>133,000</td>
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<td>Irwin Kleinman</td>
<td>Survey of Physicians' Practice, Attitudes and Behaviour Towards Informed Consent and Antipsychotic Medication</td>
<td>National Health Research and Development Program (NHRDP)</td>
<td>1995-97</td>
<td>52,600</td>
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<tr>
<td>Trudo Lemmens</td>
<td>Ethical, Legal, and Societal Issues of Behavioural Genetics</td>
<td>University of Toronto Connaught Automatic Start-Up Grant</td>
<td>1999-01</td>
<td>10,000</td>
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<td>Trudo Lemmens</td>
<td>Ethical, Legal, and Societal Issues of Behavioural Genetics</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC) New Investigator Award</td>
<td>2000-01</td>
<td>7,750</td>
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<td>Trudo and Donna Lemmens and Stewart</td>
<td>Insurance and Breast Cancer in Canada: Present Practices and Future Directions</td>
<td>Canadian Breast Cancer Research Initiative</td>
<td>1997-99</td>
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<td>Alex Levin</td>
<td>Postgraduate Bioethics Education for the 21st Century</td>
<td>Faculty of Medicine</td>
<td>2002</td>
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<td>Douglas Martin</td>
<td>Ethics of Cardiac Care Reports</td>
<td>Canadian Institutes of Health Research</td>
<td>2001-06</td>
<td>210,000</td>
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<td>Douglas Martin</td>
<td>Career Award</td>
<td>Ontario Ministry of Health</td>
<td>2002</td>
<td>59,750</td>
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<td>Douglas Martin</td>
<td>Dean's Fund Award</td>
<td>Faculty of Medicine, University of Toronto</td>
<td>2002</td>
<td>10,000</td>
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<td>Douglas Martin</td>
<td>Incorporating Technical Information and Public Values into Resource Allocation Decision-Making</td>
<td>Alberta Heritage Foundation for Medical Research</td>
<td>2002</td>
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<td>Douglas Martin</td>
<td>Priority setting in hospitals</td>
<td>Canadian Institutes of Health Research</td>
<td>2002-03</td>
<td>30,428</td>
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<td>Douglas Martin</td>
<td>Evaluating Interventions to Improve Priority Setting</td>
<td>Canadian Institutes of Health Research</td>
<td>2004-06</td>
<td>154,760</td>
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<td>Douglas Martin</td>
<td>A Global Priority Setting Research Network</td>
<td>Canadian Institutes of Health Research</td>
<td>2003-04</td>
<td>77,073</td>
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<td>Douglas Martin</td>
<td>Priority Setting Research Team: Interdisciplinary Capacity Enhancement in Priority Setting and Health Policy</td>
<td>Canadian Institutes of Health Research</td>
<td>2003-08</td>
<td>986,311</td>
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<td>Martin McKnealy</td>
<td>Critical Limits</td>
<td>The Physicians' Services Incorporated Foundation (PSI)</td>
<td>1995-97</td>
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<td>Martin McKnealy</td>
<td>Critical thinking about informed consent: A patient based empiric study</td>
<td>The Physicians' Services Incorporated Foundation (PSI)</td>
<td>1998-00</td>
<td>121,000</td>
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<td>Kathryn Morgan</td>
<td>Frankenstein revisited: Gender, biotechnology and the creation of human artifacts</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC)</td>
<td>1996-99</td>
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<td>Name</td>
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<td>Kathryn Morgan</td>
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<td>Dr. Frankenstein's Broken Promise: Bioethics and the Technologies of Sex and Gender</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC)</td>
<td>1999-02</td>
<td>51,200</td>
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<td>Elizabeth Peter</td>
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<td>Home Care Ethics: Historical Perspective in Nursing</td>
<td>Sigma Theta Tau International</td>
<td>2001</td>
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<td>Elizabeth and Patricia McKeever</td>
<td>Home Care Ethics: Identification and Analysis of Issues</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC)</td>
<td>2002-05</td>
<td>115,812</td>
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<td>Laura Shanner</td>
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<td>Reconsidering the maternal-fetal relationships: an ontological problem underlying ethical and political questions**</td>
<td>Social Sciences and Humanities Research Council of Canada (SSHRC)</td>
<td>1998-01</td>
<td>37,500</td>
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<td>Debbie and Irwin Schachter and Kleinman</td>
<td>Informed consent and stimulant medication: Adolescents' understanding of information</td>
<td>Canadian Institutes of Health Research</td>
<td>2003-07</td>
<td>219,669</td>
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<td>National Health Research Scholar Award</td>
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<td>Peter Singer</td>
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<td>The Acceptability of a Cancer Specific Living Will in Oncology Outpatients</td>
<td>Physicians Services Incorporated Foundation (PSI)</td>
<td>1995-96</td>
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<td>Peter Singer</td>
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<td>Advance directives in HIV/AIDS</td>
<td>The Physicians' Services Incorporated Foundation (PSI) and the Institute for Clinical Evaluative Sciences in Ontario (ICES)</td>
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<td>217,500</td>
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<td>Euthanasia and assisted suicide in HIV/AIDS</td>
<td>Canadian Foundation for AIDS Research (CANFAR)</td>
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<td>Resource allocation for new and emerging technologies</td>
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<td>1998-00</td>
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<td>Peter Singer</td>
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<td>Priority Setting in Hospital Programs</td>
<td>National Health Research and Development Program (NHRDP)</td>
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<td>Peter Singer</td>
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<td>A Proposal to the Change Foundation to Undertake Research on Priority Decision Making in Hospitals in Ontario</td>
<td>Change Foundation</td>
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<td>90,000</td>
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<td>Peter Singer</td>
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<td>Priority setting in hospital research</td>
<td>Canadian Institutes of Health Research</td>
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<td>Peter Singer</td>
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<td>Priority decision-making in Ontario hospitals</td>
<td>Queens University</td>
<td>2000-01</td>
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<td>Peter Singer</td>
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<td>WHO meeting on a collaborative strategy in the development of medical genetic strategies</td>
<td>Canadian Institutes of Health Research</td>
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<td>Canadian Institutes of Health Research Investigator Award</td>
<td>Canadian Institutes of Health Research</td>
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<td>Peter Singer</td>
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<td>University of Toronto MHSc in International Bioethics</td>
<td>Fogarty International Center, National Institutes of Health (US $1,193,020)</td>
<td>2000-04</td>
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<tr>
<td>Peter Singer</td>
<td>University of Toronto MHSc in International Bioethics</td>
<td>Fogarty International Center, National Institutes of Health (US $1,000,000 @ 1.22)</td>
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<td>Peter Singer</td>
<td>Health Biotechnology Innovation Systems in Developing Countries “Insight Supplement”</td>
<td>Bill &amp; Melinda Gates Foundation</td>
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<td>Peter Singer</td>
<td>Study in the area of social public engagement in healthcare decision-making</td>
<td>Charles E. Frosst Foundation</td>
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<td>Peter Singer</td>
<td>Health Biotechnology innovation systems of developing countries-publication costs</td>
<td>Rockefeller Foundation</td>
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<td>Peter Singer</td>
<td>Genomics for development, bioterrorism and human security</td>
<td>Alfred P. Sloan Foundation</td>
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<td>Peter Singer</td>
<td>Advance directives in dialysis: Follow-up study</td>
<td>National Health Research and Development Program (NHRDP)</td>
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<td>Peter Singer</td>
<td>Grand Challenges in Global Health</td>
<td>Foundation for the National Institute of Health</td>
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<td>Peter Singer</td>
<td>The Formal and Informal Curriculum in Surgical Residency Bioethics Education</td>
<td>Associated Medical Services, Inc.</td>
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<td>Peter Singer</td>
<td>Private Sector Development in Developing Countries: Targeting Local Health Needs through Health Technology</td>
<td>Rockefeller Foundation</td>
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<td>Peter Singer</td>
<td>Mobilizing Canadian Biotechnology for Global Development Needs</td>
<td>Industry Canada</td>
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<td>Peter Singer (Co-Investigator)</td>
<td>Culture and Ethics in Decision-Making Involving Aboriginal Renal Patients and Their Caregivers</td>
<td>Social Sciences and Humanities Research Council of Canada</td>
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<td>Peter Singer</td>
<td>University of Toronto Program in Applied Ethics and Biotechnology</td>
<td>Ontario Research and Development Challenge Fund</td>
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<td>Peter Singer</td>
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<td>Peter Singer</td>
<td>Canadian Program in Genomics and Global Health</td>
<td>Genome Canada</td>
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ORDCF $1.885m: U of T and other academic institutions (UHN, Hospital for Sick Children, Sunnybrook & Women’s College Health Sciences Centre) Private sector: (including GlaxoSmithKline $375,000, Merck Frosst Canada $20,000, Pfizer Canada Inc., $40,000, Sun Life Financial (see above) and other in-kind private sector contributions from individuals)
<table>
<thead>
<tr>
<th>Name</th>
<th>Executive</th>
<th>Title</th>
<th>Funding</th>
<th>Date</th>
<th>Amount</th>
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<td>Peter Singer</td>
<td>Genome Canada</td>
<td>Bridging the Genomics Divide</td>
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<td>GC 1,415,003; IDRC $200,000; Indian Council for Medical Research et al $50,000; EMRO $50,000; Ontario Centre for Agricultural Genomics $105,000; University of Guelph College of Arts $23,000; Merck $200,000; PAHO $19,000; Keck Graduate Institute $272,000</td>
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<td>Peter Singer</td>
<td>Genome Canada</td>
<td>Information and Communication Technology Platform for Public Engagement to Optimize Canadian Innovation</td>
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<td>1,220,844</td>
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<td>Peter Singer</td>
<td>Genome Canada</td>
<td>Strengthening the Role of Genomics and Global Health</td>
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<td>2005-09</td>
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<td>Peter Singer</td>
<td>Genome Canada</td>
<td>Ethical, Social, and Cultural Issues in Grand Challenges in Global Health Program Projects</td>
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<td>Leigh Turner</td>
<td>Social Sciences and Humanities Research Council of Canada</td>
<td>Bioethics, Casuistry, and Culture: Practical Moral Reasoning in Multiethnic Settings</td>
<td>1999-02</td>
<td>128,550</td>
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<td>Ross Upshur</td>
<td>Cancer Care Ontario</td>
<td>Policy analysis of informed consent issues in Pap smear registry</td>
<td>2000-01</td>
<td>18,000</td>
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<td>Ross Upshur</td>
<td>CIHR</td>
<td>Addressing gender differences in colorectal cancer screening</td>
<td>2005-08</td>
<td>$206,260</td>
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<td>Ross Upshur</td>
<td>Health Canada</td>
<td>Effect of Ontario's universal influenza program (UIIP) on influenza-related health care.</td>
<td>2005-05</td>
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<td>Ross Upshur</td>
<td>CIHR</td>
<td>A study to assess the utility of a Canadian web-based research ethics board (REB) protocol and consent review template.</td>
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<td>Evaluating interventions to improve priority setting</td>
<td>2004-06</td>
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<td>Association for Surgical Education Foundation (CESERT grant)</td>
<td>Formal &amp; informal curriculum in surgical residency bioethics education.</td>
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<td>Ross Upshur</td>
<td>Ontario Ministry of Health &amp; Long-Term Care</td>
<td>Primary Care Atlas</td>
<td>2004-06</td>
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<td>Ross Upshur</td>
<td>CIHR</td>
<td>Collection, use and disclosure of personal health information: The Health Care Information Directive applied to genetics</td>
<td>2004-06</td>
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<td>Ethical challenges in preparedness &amp; response for SARS: an interdisciplinary research study.</td>
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<td>Ross Upshur</td>
<td>City of Toronto Department of Public Health</td>
<td>SARS quarantine evaluation/ community transmission.</td>
<td>2004-05</td>
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<td>Ross Upshur (co-applicant)</td>
<td>Lessons in epidemiology and genetics of adult cancers from youth: Pilot studies in Ontario.</td>
<td>Canadian Breast Cancer Foundation</td>
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<td>Ross Upshur</td>
<td>A bioethical analysis of vaccine preparedness, testing, and delivery</td>
<td>Networks of Centres of Excellence (CANVAC program)</td>
<td>2003-05</td>
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<td>Ross Upshur</td>
<td>Project examining the effectiveness of ethics services (PEECE)</td>
<td>University of Toronto</td>
<td>2003-04</td>
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<td>The Time Series Project</td>
<td>CIHR</td>
<td>2002-04</td>
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<td>Ross Upshur</td>
<td>Implementing privacy and confidentiality in health networks</td>
<td>Networks of Centres of Excellence – HEALnet</td>
<td>2002-04</td>
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<td>Ross Upshur</td>
<td>Patient perspectives on oral vitamin B12 therapy in the primary care setting</td>
<td>Physicians Services Incorporated Foundation (PSI)</td>
<td>2002-03</td>
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<td>Ross Upshur</td>
<td>Effects of socioeconomic status on mortality &amp; health services utilization after initial admission for community-acquired pneumonia in the elderly</td>
<td>CIHR – Integrated Health Research Team (led by Mark Loeb)</td>
<td>2001-03</td>
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<td>The Health Care Information Directive</td>
<td>Health Canada</td>
<td>2002-03</td>
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<td>Bridging the gap: The relationship between evidence and values in health care – An empirical and conceptual program of research</td>
<td>Canadian Institutes of Health Research (CIHR) New Investigator Award</td>
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<td>CIHR</td>
<td>2005-08</td>
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<td>Patricia (Caulfield) Wall</td>
<td>Would communication improve prescribing for seniors? (co-applicant)</td>
<td>Canadian Health Services Research Foundation</td>
<td>2002-03</td>
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<td>Charles Wejer</td>
<td>Protecting communities in research: philosophical and pragmatic challenges</td>
<td>National Bioethics Advisory Commission (NBAC)</td>
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<td>The ethics of genetic research on communities</td>
<td>National Institutes of Health (NIH)</td>
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<td>Conceptual problems in research ethics**</td>
<td>Medical Research Council (MRC)</td>
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<td>Donna Wells</td>
<td>Development of a Reconceptualized Program of Discharge Making and an Evaluation Design to Examine Its Validity and Practice</td>
<td>Social Sciences and Humanities Research Council of Canada</td>
<td>1995-96</td>
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<td>Program Evaluation of an Integrated Model of Discharge Planning</td>
<td>Social Sciences and Humanities Research Council of Canada</td>
<td>1998-00</td>
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</table>

54,834,443
APPENDIX 5
FINANCIAL STATEMENT

The following are financial figures for the JCB as of July 1, 2005.

The JCB promotes a diverse, global and multidisciplinary approach to bioethics and is supported from various sources. The larger share of funds (63%) come from Canadian and U.S. government funding agencies to support innovative, internationally recognized programs in priority setting, global health, genomics, end of life care and clinical care. The second largest shares (28%) comes from University of Toronto and Partners. The industry sector share is 4% and 5% comes from individuals and foundations.

Numerous national and international research projects, clinical trials, university chairs and programs are supported by private industry, gifts, and endowments, including those in bioethics. Many government research grants, such as the Ontario Research and Development Challenge Fund (ORDCF) require university researchers to obtain matching private sector funds.

Management of JCB finances and programs is overseen by a Advisory Board of Directors chaired by Catharine Whiteside, Vice-Provost, Relations with Healthcare Institutions. An internal advisory committee provides strategic advice to the Director. The JCB abides by the financial and academic rules and regulations of the University of Toronto.

Of the 216 JCB members, about 28 are full-time bioethicists employed by the 15 health care organizations and/or the university. The remaining members incorporate bioethics into their clinical duties as doctors, nurses and social workers. Some receive research and travel grants through the JCB and other university departments; some accept consulting fees from public and private sector organizations.

Sources of Funding

To get an overall picture of the JCB’s annual operating funding, the funding is divided into four sources: academic institutions, government, individuals and foundations, and private sector. Where the funds are per annum, they are included directly in these calculations. Where the funds are held for a fixed term, they are divided by the number of years to provide an annualized amount. Where the funds are endowed, or unrestricted as to term, an annualized amount was calculated by assuming 5 per cent interest would be expended each year. A breakdown of the funding with more specific information is provided below for JCB annual operating funds by source for fiscal 2005.

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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<td>University of Toronto &amp; JCB Partners</td>
<td>$2,700,933</td>
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<tr>
<td>Government</td>
<td>$6,119,127</td>
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<tr>
<td>Individuals and Foundations</td>
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<td>Industry</td>
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<td><strong>Total</strong></td>
<td><strong>$9,661,084</strong></td>
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</table>

Joint Centre for Bioethics, Funding Breakdown, annualized, as at July 1, 2005

1. Core operating funds
The University of Toronto and fifteen health care partners contribute to the operating budget of the JCB. This budget is used to support JCB administrative staff and portions of salaries of JCB academic administrators, supplies and services, travel for JCB members and graduate students, and equipment. The total annual budget is $923,238.

2. Salaries of JCB members
JCB has update in the participating organizations. About 30 hospital and university-based bioethicists work full-time in bioethics. They are employees of the university or one of the participating health care organizations. Assuming an average salary of $75,000 pa for these 30 individuals, the salaries paid by teaching hospitals and the University of Toronto to bioethicists who are JCB members is $1.5 million pa.
3. Space
The JCB occupies 2,454 square feet (228 sq metres) at 88 College Street. The bioethicists also have offices in fifteen health care organizations. The notional rent and maintenance on this space is significant, provided by academic institutions, and is not included in these calculations.

4. U of T Chair in Bioethics
U of T has 170 endowed department chairs. In 1996 Sun Life Assurance Company donated $1 million, matched by $1m from U of T, to create a chair in Bioethics. The interest on the $1 million donation is used to support the Sun Life Financial Chair (P. Singer). The policies on endowed chairs apply.

- The Provost opened a tenure stream position in bioethics at University of Toronto
- $10,000 pa in research funds to chair-holder, Dr. P.A. Singer.
WORKING FOR AN ETHICAL FUTURE
We would like to thank Michael Keating for writing this document