A significant challenge for the organ transplant community is the critical shortage of organs. In the past decade, over 70,000 individuals have died while waiting for an organ transplant. The inadequate supply of organs from deceased donors has prompted an increasing reliance on organs from living donors. There are now more than 7,000 transplants per year from using organs from living donors, representing nearly 50% of the solid organ donors in the United States. Living donors are a unique patient population who bear the risks of a procedure while the benefits go to another. The medical community justifies engaging in this practice due to respect for the autonomy of the donor as well as the significant benefit to the recipient, but this combination raises significant ethical and policy issues.

Until recently there have been no studies of informed consent among living donors. A number of investigators have found that the decision process by living donors relies heavily on moral reasoning rather than a deliberative reasoning process. These studies have found that the majority of donors decide to proceed with organ donation based on the potential to provide significant benefit to the recipient rather than on careful weighing of the risks and benefits of donation to themselves. While there has been no prospective study of how much donors understand about risks and benefits of donation at the time of informed consent, some authors contend that relying on moral reasoning rather than a deliberative process precludes the donor from considering alternatives. They argue that donors seek information to reaffirm their decision or filter out negative information or doubts rather than weighing the risks and potential benefits involved. Therefore, the validity of informed consent is at issue.

Whether living donors are persuaded, manipulated, or coerced to donate is not known. Transplant professionals and programs go to great lengths to set up systems and safeguards to inform donors and to detect substantially manipulated or coerced consents but there is little evidence about whether these safeguards are effective. Studies of the psychosocial impact of living kidney donation support the notion that many donors feel obligated to donate. 

Recently, Centers for Medicare and Medicaid Services (CMS) responded to the fact that consent content and practices are different across transplant centers, and moved to standardize the content of information given to living donors. The proposed standard requires centers “to provide information to prospective living donors regarding all aspects of and potential outcomes from living donation, such as the evaluation process, surgical procedure, alternative treatments for the transplant patient, potential medical and psychosocial risks to the donor, specific transplant outcomes for both donors and recipients, and potential future health and life insurance coverage problems related to living donation.” While this is an important step, it is hard to know if this will indeed result in more substantive informed consent in this population, especially if donors absorb only the information that reaffirms their decision and they make a decision to act as a living donor.
The National Institutes of Health (NIH) has recognized that as living donors become an increasing source of solid organs for transplant, it is crucial to systematically answer questions about the outcomes and decision making related to living donation. In 2006, the Renal and Lung Living Donors Evaluation Study (RELIVE) project brought together a consortium of transplant programs to study the medical and psychosocial consequences of donating a kidney or lung. This study has also funded the first prospective study of informed consent in these living donors. Through this prospective observational study, we hope to answer some of the questions around living donation:

1. How well do donors understand the short and long term medical, emotional, and financial consequences of organ donation?

2. Does the information that donors receive influence their decision to donate?

3. Do living donors experience pressure to donate?

4. If donors do experience pressure, are there predictors of who is at risk for making decisions that do not meet standards of informed consent?

It is only by answering these questions that we can determine how to better protect those who decide to become living donors.

**References:**

2008 Bioethics Seminars

The Center provides a range of opportunities for faculty, students, staff and the public to learn about cutting edge issues in bioethics through an annual seminar series. Seminars are held 12:15 to 1:30 pm, in 3-125 Mayo Memorial Building on the University of Minnesota campus.

Oct 10 “The Case of the Psychopath Psychiatrist,” by Carl Elliott, MD, PhD, Professor, Center for Bioethics, Department of Pediatrics, University of Minnesota Medical School; and Department of Philosophy, University of Minnesota. Seminar can be viewed in Breeze format at www.bioethics.umn.edu.

Nov 14 “Shopping for Health Care in the Global Marketplace: Moral Dimensions of “Medical Tourism,” by Leigh Turner, PhD, Associate Professor, Center for Bioethics; and Division of Health Policy and Management, School of Public Health, University of Minnesota.

Facility Publications

BOOK

BOOK CHAPTERS


ARTICLES


NEW Masters Program in Bioethics

The Center for Bioethics is proud to announce that the University of Minnesota Board of Regents approved a new, interdisciplinary Master of Arts (MA, Plan A) degree with a major in Bioethics (Twin Cities Campus). The new program will enroll its first students in Fall 2009.

This new graduate program will be offered and housed in the Center for Bioethics, drawing on its large interdisciplinary faculty.

Information on application and admissions for the new Master’s Degree in Bioethics is available at www.bioethics.umn.edu. If you have specific questions or would like to be added to our email list to receive information when it becomes available, email oneil169@umn.edu.

Spring 2009 Bioethics Courses

BTHX 5000 Section I: Topics in Bioethics
Section II: Medical Humanities: Literature and Medicine

BTHX 5900 Independent Study in Bioethics

BTHX 8114/ (GCC 8914 Ethical and Legal Issues in Genetic Counseling
BTHX 8610 Medical Consumerism
BTHX 8900 Advanced Independent Study in Bioethics

For more information: www.bioethics.umn.edu

Fall 2008 Mini Bioethics School

LATE-BREAKING BIOETHICS AND THE ART OF MEDICINE
6:00 - 8:00 pm, Thursdays; November 13 & 20, December 4

THIS YEAR
Learn about cutting edge issues in bioethics. ethical issues in organ transplantation, medical tourism and the global medical marketplace; and the relationship between the arts and medicine. This course hosted is by Center for Bioethics and taught by Center faculty, and will explore ethical challenges in rapidly advancing areas of health care.

$45 registration fee—includes course materials and refreshments.
3-125 Mayo Memorial Building, 425 Delaware Street SE, Minneapolis, MN University of Minnesota Twin Cities Campus

SCHEDULE
THURSDAY, NOVEMBER 13 “Ethics and Organ Transplantation: From Donation after Death to Matching Donors on the Web” - Jeffrey Kahn, PhD, MPH

THURSDAY, NOVEMBER 20 “Shopping for Health Care in the Global Marketplace: Ethics of Medical Tourism” - Leigh Turner, PhD

THURSDAY, DECEMBER 4 “Imagining Medicine: Understanding Illness through Literature and the Visual and Performing Arts” - Mary Faith Marshall, PhD

FOR MORE INFORMATION, GO TO:
www.ahc.umn.edu/outreach/minibioethics/home.html.

Mary Faith Marshall, PhD teaches mini-bioethics on December 4.
A Call to Action

Your Contribution Makes a Difference

Research done by the Center’s faculty reverberates in hospitals, research labs, and throughout the University of Minnesota. Our partnerships with the University of Minnesota, the Law School, the College of Nursing, and the School of Medicine and Dentistry have laid the groundwork for many of the most challenging bioethical issues of our time.

The Center for Bioethics' commitment to sharing its work with the world is demonstrated by EthicShare, or in its project on preparing for catastrophic health issues such as an influenza pandemic.

From the bedsides of dying patients where physicians and families confront critical choices to national and state capitols where legislators struggle to shape equitable health care policies, individuals, institutions, and society as a whole are grappling with bioethical issues.

There are many opportunities to promote and be a part of the innovative work of the Center for Bioethics. A recent gift from James G. and Laura H. Miles established the Center for Bioethics Unrestricted Endowment, an endowment that will provide ongoing funding to advance the work of the Center as important bioethical issues and research opportunities are identified.

It is the hope of the Miles family that others will also support the work of the Center with gifts to this unrestricted endowment fund. You are invited to contribute to the Center for Bioethics Unrestricted Endowment. By doing so, you will become an advocate for research, education, and discussion on critical bioethical issues.

To make a gift and to receive information on how your contribution can make a difference, please contact Holly McDonough at the Minnesota Medical Foundation at 612-625-1440/800-922-1663 or h.mcdonough@mmf.umn.edu.

Center News

Jeffrey Kahan, PhD, MPhil, has been appointed as the Distinguished McKnight Professor Selection Committee, University of Minnesota.

Steven Miles, MD, has been named one of the 100 Influential Health Care Leaders for 2008 by Minnesota Physician.

Steven Miles, MD, has been named Human Rights Hero, Section of Individual Rights and Responsibilities, American Bar Association, 2008.

Maryam Valapour, MD, has been appointed to the Health Policy Committee, American Thoracic Society.

Pandemic Flu Project Update

The Minnesota Pandemic Ethics Project is a collaborative venture of the University of Minnesota Center for Bioethics and the Minnesota Center for Health Care Ethics, and is funded by the Minnesota Department of Health (MDH). The aim of the project is to provide ethical guidance concerning the rationing of scarce resources during an influenza pandemic. The project has submitted preliminary recommendations to MDH, and is now designing public engagement activities. In addition to issuing a traditional call for public comments, the project team plans to actively engage community members in a series of small group discussions. The goals of these discussions are twofold:

- elicit Minnesotans’ responses to preliminary ethical recommendations developed from a population health perspective for rationing health-related resources in Minnesota during a severe influenza pandemic.

These discussions will be held at six sites around the state: four in the Twin Cities metro area, and two in greater Minnesota. The project’s recommendations will be modified in light of the feedback received.

Bioethics Graduate Minor Student wins “Best Dissertation Award”

Pamela Bjorklund, a student in the School of Nursing and Graduate Minor Student in Bioethics, has been selected as the University of Minnesota (UMN) nominee for the 2008 national CGS Social and Behavioural Sciences award. The UMN Graduate School selected Bjorklund’s dissertation to forward to the national Council of Graduate Schools (Washington, DC) distinguished dissertation award competition for 2008.

Our congratulations to Ms. Bjorklund for this prestigious award!