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PUBLICATIONS

Faculty Publications *Continued from Page 6*

Elliott C. Lost and Found: Guinea Pig Zero.
Tin House 2008 Spring:103-105.

Garrett J, Vawter D, Prehn A, **DeBruin D**, Gervais K.
Ethical Considerations in Pandemic Influenza
Planning. *Minnesota Medicine* 2008;91(4):37-39.

Kahn J. Symposium: Creating Stem Cells by Research
Cloning: Scientific, Ethical, Legal & Policy
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Technology* 2008;9(1):125-130.

Faden R, Mastroianni A, **Kahn J.** Health Research
and the HIPAA Privacy Rule [Letter]. *JAMA*
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Gene Transfer Clinical Trials. *Human Gene Therapy*
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Miles S. Doctors' Complicity with Torture: It is Time
for Sanctions. *British Medical Journal*
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Satin D. Colleague Interview: A Conversation with
David Satin, MD. *MetroDoctors* 2008;10(5):11-13.

Turner L. 'Medical Tourism' Initiatives Should
Exclude Commercial Organ Transplantation. *Journal
of the Royal Society of Medicine* 2008;101(8):391-394.

Turner L. Cross-Border Dental Care: 'Dental
Tourism' and Patient Mobility. *British Dental Journal*
2008;204:553-554.

Turner L. Politics, Bioethics, and Science Policy.
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BIOETHICS



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UNIVERSITY OF MINNESOTA

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EXAMINER

2008
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Informed Consent Among Live Organ Donors

by Maryam Valapour, MD

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.¹ 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.¹ 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.²⁻⁴ 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.⁵ 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 donors⁶ and to



Maryam Valapour, MD

detect substantially manipulated or coerced consents but there is little evidence about whether these measures are effective. Studies of the psychosocial impact of living kidney donation support the notion that many donors feel obligated to donate.^{4,7-8} If this obligation motivates a donor to investigate her options and results in the decision to donate an organ, then the decision can be viewed as compatible with a voluntary consent and as an autonomous act. If the obligation is experienced in such a way that a donor feels she cannot refuse donation, then we have reason to worry that the decision is not autonomous and therefore does not qualify as informed consent. Too few studies have been done to make any conclusions about the form and level of influence donors experience when they make a decision to act as a living donor.⁹⁻¹³

Recently, Centers for Medicare and Medicaid Services (CMS) responded to the fact that consent content and practices are different across transplant centers,¹⁴ 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."¹⁵ 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 filter out information that may undermine it.

Continued on Page 2

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"More than 20 years of leadership in bioethics."

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ISSUE

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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?
- 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 then determine how to better protect those who decide to become living donors.

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3. Fellner C, Marshall J. Kidney Donors—The Myth of Informed Consent. *Am J Psychiatry* 1970;126:1245-1251.

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Calendar of Events

Oct 13-Nov 10

David Satin, MD, will host the University of Minnesota's Mini Medical School "Hot Topics in Health," Minneapolis, MN. For information: www.ahc.umn.edu/outreach/minimed/fall2008/home.html.

Oct 23-26

American Society for Bioethics and Humanities (ASBH) Annual Meeting, Cleveland, OH.

10/23 Jeffrey Kahn, PhD, MPH, will present "EthicShare: A Future of Bioethics Research and Community Exchange"; David Satin, MD, will moderate "The Meaning of Translation: Implications of Translational Research for the Future of Medical Research and Clinical Practice";

10/24 Barbara Koenig, PhD, will moderate and Debra DeBruin, PhD; Joan Liaschenko, PhD, will participate on a panel "Future Directions for Public Health Emergency Planning: Broader Moral Perspectives"; John Song, MD, MPH, will present "An Intervention to Facilitate End-of-Life Planning Among Homeless Persons";

10/25 Mary Faith Marshall, PhD, will moderate "Rationing in a Severe Pandemic: Canadian and Minnesotan Perspectives";

10/26 Mary Faith Marshall, PhD, will speak on "New Perspectives on Ethics Consultations."

For information: www.asbh.org/meetings/annual/.

Oct 31

Steven Miles, MD, will present "Financing of Health Care," at the "Tough Problems: Artful, Ethical Solutions" Conference, University of Minnesota, Continuing Dental Education, School of Dentistry, St. Paul, MN. For information: www.dentalce.umn.edu/dentalce/coursecalendar/EthicalSolutions/home.html.

Oct 31

John Song, MD, will moderate "Cultural Perspectives on End of Life Care," at the Minnesota Many Faces of Community Health Conference, St. Louis Park, MN. For information: www.manyfacesconference.org/agenda2008.html.

Nov 2

Mary Faith Marshall, PhD, will speak on "Oh, the Water! Lessons from Katrina in Planning for Pandemics and Other Disasters," at the Association of American Medical Colleges, San Antonio, TX. For information: www.aamc.org/meetings/annual/.

Nov 2

David Satin, MD, will lead a discussion after the matinee performance of "A Plague of Angels," the compelling drama based on the true story of Mary Mallon, an Irish immigrant in turn-of-the-century New York, who became infamous as "Typhoid Mary." The performance will be held at Theatre in the Round, 245 Cedar Avenue, Minneapolis, MN. For more information: www.TheatreintheRound.org or call 612-333-3010.

Nov 11

Debra DeBruin, PhD, will speak on "Ethics and Public Health Emergencies: How Should We Prepare for Pandemic Flu?," at the Department of Psychiatry & Psychology Grand Rounds, Mayo Clinic, Rochester, MN. For information call 612-624-9440.

Nov 13-16

Muriel Bebeau, PhD, will present "Rest's Four Component Model at Twenty-Five: Recent Developments in Research and Practice," at the Association for Moral Education Annual Meeting, University of Notre Dame, South Bend, IN. For information: www.nd.edu/~ame2008/index.shtml.

Nov 19

Carl Elliott, MD, PhD, will speak on "Guinea Pigs of the World, Unite!" at the Public Responsibility in Medicine and Research (PRIM&R) Conference, Orlando, FL. For information: www.primr.org/Conferences.aspx?id=3643.

Nov 20

Carl Elliott, MD, PhD, will speak at the Mississippi Philosophical Association Medical Ethics Conference, Jackson, MI. For information: www.olemiss.edu/orgs/mpa/conferences.htm.

Nov 20

Mary Faith Marshall, PhD, will speak at Pediatric Grand Rounds, Children's Hospital of the Kings Daughter, Norfolk, VA. For information: www.chkd.org/Services/DeptPeds/Education.aspx.

Nov 21

Barbara Koenig, PhD, will participate in a panel discussion "Direct-to-Consumer Genomics Companies: Anthropologists in New Territory," at the American Anthropological Association Annual Meeting, San Francisco, CA. For information: www.aaanet.org/meetings/.

Jan 19-23

David Satin, MD, will speak on "Managing Cultural Conflicts in Medicine"; "Treating Non-Patients"; and "Comparisons of Canadian and US Health Care: Is Single Payer the Way to Go?" at the 32nd Annual Family Medicine Update Conference, North Dakota Medical Association, Big Sky, MT. For information: www.ndafp.org/xBig_Sky.asp.

Feb 10

Dianne Bartels, RN, MA, PhD, will present "Ethical Challenges in End of Life Care," at the St. Paul Senior Workers Association, St. Paul, MN. For information: www.seniorworkers.org/SPSWA_New/index_sp.htm.

Feb 23-24

Muriel Bebeau, PhD, will present "Educating for Social Responsibility," at the University of British Columbia, Vancouver, BC, Canada. For information call 612-625-5138.

Feb 26

Dianne Bartels, RN, MA, PhD, will present "Ethical Challenges in End of Life Care," at the Minneapolis Senior Workers Association, Minneapolis, MN. For information: www.seniorworkers.org/mps_index.htm.

2008 Bioethics Seminars

Continuing Medical Education (CME) credit available

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



DEC 14
"Beyond the Bench: The Role of Research Ethics Consultation Service," by Jennifer McCormick, PhD, General Internal Medicine, Mayo Clinic.

The University of Minnesota designates this educational activity for a maximum of 1 AMA PRA Category 1 Credit™. Physicians should only claim credit commensurate with the extent of their participation in the activity. The University of Minnesota is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

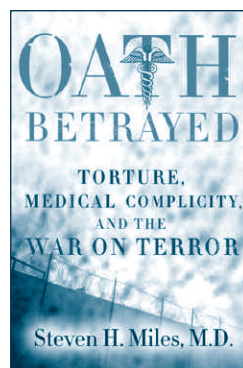
Registration is required if you are attending for CME credit.

For more information visit www.bioethics.umn.edu.

Faculty Publications

BOOK

Miles S. *Oath Betrayed: Torture, Medical Complicity and the War on Terror*. Random House, 2006. Issued in translation Baison Publishers, Seoul, Korea, 2008.



BOOK CHAPTERS

Bebeau M, Monson V. Guided by Theory, Grounded in Evidence: A Way Forward for Professional Ethics Education. In Nucci L, Narvaez D (eds.) *Handbook on Moral and Character Education*. Routledge, New York, NY, 2008.

Dingel M, **Koenig B.** Tracking Race in Addiction Research. In Koenig B, Lee S, Richardson S (eds.) *Revisiting Race in a Genomic Age*. Rutgers University Press, Piscataway, NJ, 2008.

ARTICLES

Elliott C. In Defense of the Beta Blocker. *The Atlantic.com* 2008; available at www.theatlantic.com/doc/print/200808u/beta-blockers.

Elliott C, Abadie R. Exploiting a Research Underclass in Phase I Clinical Trials. *New England Journal of Medicine* 2008;358(22): 2316-2317.

Elliott C. Pappworth's Guinea Pigs. *Biosocieties* 2008;3:147-149.

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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 by 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 Topics in Bioethics
Section I: Morality and Risk
Section II: Medical Humanities: Literature and Medicine
BTHX 5900 Independent Study in Bioethics

BTHX 8114 /GCD 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



University of Minnesota
Medical Students Amanda
Schlessinger and Michael
Parrott

Research done by the Center's faculty reverberates in hospitals, research labs, scientific journals, policy arenas, and throughout the University of Minnesota. Our partnerships with the University of Minnesota Law School, Medical School, School of Nursing, School of Public Health, University Libraries, Department of Computer Science and Engineering, and with universities across the country and around the world demonstrate our multi-disciplinary and collaborative approach to addressing some of the most challenging bioethical issues of our time.

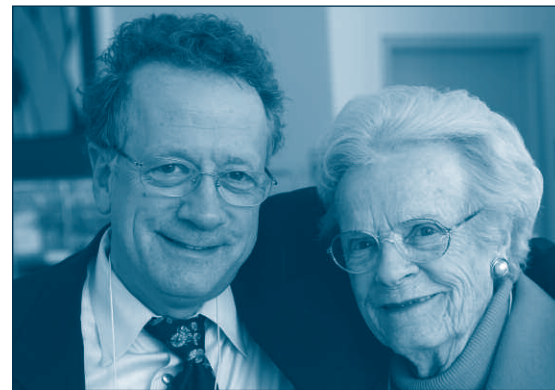
The Center for Bioethics' commitment to sharing its work with the wider community is demonstrated by EthicShare, or in its project on preparing for catastrophic health issues such as an influenza pandemic.

From the bedsides of dying patients where physicians and family members 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. The Center for Bioethics leads the way with research, education, public discussion, and community outreach.

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.

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 important, 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.



Steven Miles, MD; Laura Miles

Center News

Jeffrey Kahn, PhD, MPH, has been appointed to 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' ethical guidance regarding rationing of health-related resources to protect the population's health in the state during a severe influenza pandemic, noting the range of perspectives and advice and common value commitments.

- 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.

Announcing New Bioethics Faculty



Leigh Turner, PhD

The Center for Bioethics is pleased to announce **Leigh Turner, PhD**, recently joined the faculty as an Associate Professor. Professor Turner joins the Center core faculty, and is Faculty in the Division of Health Policy and Management in the School of Public Health and the

Department of Pharmaceutical Care & Health Systems in the College of Pharmacy. Prior to his arrival in the Twin Cities, Turner was an Associate Professor and William Dawson Scholar in the Biomedical Ethics Unit at McGill University in Montreal. His current research examines ethical issues related to "medical tourism" and the emergence of a global marketplace in health services. Related work explores the ethics of cross-border commercial organ transplantation. Turner's teaching duties include offering the Ethics in Public Health: Professional Practice and Policy course within the School of Public Health. We are thrilled to welcome Professor Turner to the Center and to the University community.

WELCOME

Professor Leigh Turner's current research examines ethical issues related to "medical tourism" and the emergence of a global marketplace in health services. Related work explores the ethics of cross-border commercial organ transplantation.

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 Behavioral 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!