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**Involving the Public in Planning for the Genomics Revolution:
 An Experiment in Deliberative Democracy**

by Ashley Hicks, Joan Henriksen Hellyer, RN, PhD, and Barbara Koenig, PhD

Mayo Clinic Bioethics Research Program

The X Prize Foundation is offering ten million dollars to the first group able to sequence 100 human genomes in ten days for less than \$10,000 per genome. Companies like 23 & Me, Navigenics, and deCODE offer products like deCODEme directly to consumers. The stakes are high as the biomedical establishment plans for the advent of “personalized medicine.” If targeted treatment is to offer real cures (not just quick profits), it will require a massive research effort. Large numbers of people will need to participate in research that tracks the progression of disease—and the foundations of health—over long periods of time. Information from medical records, data about environmental exposures, and an individual’s genome will need to be linked. These new data bases, often called “biobanks,” will allow researchers unprecedented access to biospecimens along with the statistical power to unlock previously unknown genetic associations. However, the potential benefits of biobanking will only be realized if scientists earn and maintain the trust of citizens who

donate samples. What should be done to ensure the public’s trust?

Identifying Public Concerns

In addition to the inherent risk to privacy of linking genetic information with medical records, new National Institutes of Health guidelines require that all genomic data gathered with public funds be “de-identified” and shared with other scientists. Some experts question whether de-identification of DNA is even possible, given that an individual’s sample may be found in many other data bases, such as those used by law enforcement or online genealogy companies. Apprehensions are compounded by congressional failure to pass strong federal genetic anti-discrimination laws. In spite of the example of Iceland and other pioneering biobanks, we don’t yet have a good idea how to solve the myriad problems raised by biobanks. Furthermore, techniques for ascertaining public views about the regulation of particular scientific projects have not kept up with the

Continued on Page 2

The Research Team – Barbara Koenig, PhD, Joan Henriksen Hellyer, RN, PhD, Ashley Hicks

Barbara Koenig, PhD, an anthropologist who studies contemporary biomedicine, is Faculty Associate at the Center for Bioethics, University of Minnesota, and Co-Director of the Program in Professionalism and Bioethics at Mayo Clinic, Rochester. Dr. Koenig’s empirical bioethics research focuses on two areas: end-of-life care and the ethical, social, and political implications of new biomedical technologies, particularly those within the genomic sciences.

Joan Henriksen Hellyer, RN, PhD, is a post-doctoral research fellow in the Bioethics Research program at Mayo Clinic, Rochester. She received her doctoral degree from the University of Iowa in Religious Studies in 2007.



Ashley Hicks, Barbara Koenig, PhD

Her research interests include virtue ethics, professional ethics, and informed consent in human subjects research.

Ashley Hicks is a research assistant in the Bioethics Research program at Mayo Clinic, Rochester. She graduated from Wellesley College in 2006 and will begin graduate studies in public health, bioethics, and social work in the fall of 2008.



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**IN THIS
 ISSUE**

Faculty Publications . . . pg. 3
 EthicShare pg. 4
 Center News. pg. 5
 Calendar of Events pg. 7



Assuming that public values should guide the direction of biotechnology, how should we engage the public?

pace of discovery. Direct votes and polling have limited utility when considering highly complex arenas of biomedical science, and traditional methods of consulting with the public can easily be taken over by special interests. Assuming that public values should guide the direction of biotechnology, how should we engage the public?

What Is Deliberative Democracy?

Mayo Clinic, along with medical centers and governments around the world, is planning for a future when DNA biobanks will be central to both research and clinical care. Researchers anticipate that initial donors for a proposed biobank will include residents of Olmsted County where Mayo Clinic is located. Barbara Koenig, Faculty Associate at the Center for Bioethics and Professor of Medicine at Mayo Clinic, is experimenting with a technique called “deliberative community engagement” in order to elicit Olmsted County community members’ concerns and hopes for a biobank. Based on theories of deliberative democracy, our research group sought to engage community members in open dialogue. The approach assumes that once informed and provided with an opportunity for deliberation, non-expert members of the public are fully capable of reflecting on highly complex, technical issues. Participants work to understand each other and determine areas of agreement and disagreement; they both form and test their judgments within the collective discussion.

Olmsted County Event

For two weekends (four full days) in September 2007, a group of 20 citizens met in Rochester to discuss plans for a DNA biobank at Mayo Clinic. Participants were randomly recruited to match Olmsted County demographics, with over-sampling to allow representation of minority groups. Each person was paid \$400. Participants received a booklet written specifically for the event as well as access to web-based background material. On the first day, deliberants interacted with experts in the field of biobanking and genetic research; they listened to and questioned speakers on the utility of DNA research, concerns of populations such as Native Americans, and the perspectives of patient privacy advocates. Education

established a basic working knowledge of biobanks that provided a common language for group discussion. However, education by itself is an inadequate way to involve the lay public in science policy. Our goal was not to correct a knowledge deficit, but to enable authentic deliberation and trade-offs among competing values. What risks will the public accept in order to gain the benefits of genomic research?

With the aid of professional facilitators, the deliberants spent three full days debating these questions and formulating recommendations. Participants met in small groups composed of six or seven deliberants to explore members’ hopes and concerns about biobanking at Mayo Clinic. Each group was charged with making recommendations for the biobank’s operation and oversight based on the key values they had identified. On the final day, participants gathered together to listen to each small group’s report. At this critical juncture, deliberants actively debated which recommendations would convey their shared concerns. The final group exercise was, in some ways, the most difficult. Individual participants had to consider not only their own values and preferences, but also those of hypothetical strangers and the community as a whole. They made recommendations about the governance of an ideal biobank. The deliberants were keenly aware that, in the real world, limits might slow research while a lack of guidelines could put donors at risk. In the face of competing interests and following debate and compromise, the participants agreed on specific recommendations that each could endorse. See “Initial Deliberant Recommendations.”

INITIAL DELIBERANT RECOMMENDATIONS

Interaction with donors

- Develop a simple informed consent process that is not burdensome to potential DNA donors or researchers.
- Explore various modalities and procedures for providing information and obtaining consent (i.e. video, in person, written document).
- Accommodate cultural differences and language needs during the consent process.
- Proceed with donation only if participants understand the following:
 - 1) purpose of the DNA collection;
 - 2) sample handling and duration of storage; and
 - 3) possible research uses of samples.

Community involvement

- Develop proactive community education materials about genomics research and DNA biobanking.
- Include authentic and ongoing community involvement in the oversight of the biobank's operations in order to be transparent and to enhance accountability.
- Create a mechanism (newsletter, website, or other public forum) to regularly inform biobank participants about new research proposals.

Options for participation

- Maintain a data management system that allow donors to withdraw their sample from the biobank at any time.
- Obtain broad consent (e.g. “blanket consent”) from donors initially, but allow them to withdraw from (or “opt out”) of specific types of research.

Sample sharing and accountability

- Establish transparent standards for sharing DNA with third-party researchers outside of Mayo Clinic, especially those in the for-profit sector and the military.
- Design mechanisms to ensure that third-party researchers comply with Mayo Clinic standards.
- Create policies to establish Mayo Clinic's accountability for any misuse of samples or breaches in security.

Next Steps

The bioethics research team is now analyzing the wealth of information generated from this experiment. Follow-up interviews with participants are in progress to solicit feedback, to clarify their original positions on the group's recommendations, and to investigate whether their views have changed

in the months since the event took place. The participants' recommendations will be used by Mayo Clinic in formulating the guidelines for the operation of a proposed biobank. Participants will have the opportunity to review and comment before the collection of DNA samples begins. Final decisions on the role of continued input and possible community oversight have yet to be made.

The results of this experiment in deliberative community engagement will be compared to the outcomes of a similar event organized by Michael Burgess, a researcher at the Centre for Applied Ethics at the University of British Columbia. Future deliberations are planned at other U.S. locations and in Australia, further testing this approach to empowering citizens in democratic societies. The Minnesota Department of Public Health, working with the Center for Bioethics at the University, and the Minnesota Center for Healthcare Ethics plans to use deliberative democracy techniques to engage local communities in pandemic flu planning. This approach enables citizens to articulate key values, identify persistent disagreements, and make real trade-offs. If community recommendations are taken seriously, engagement promotes public trust in the scientific process, a critical ingredient for projects—such as biobanks or flu planning—that demand the participation of many.

This research was supported by funding from Mayo Clinic, Rochester and the National Human Genome Research Institute.

FOR MORE INFORMATION

The Olmsted County event: http://mayoresearch.mayo.edu/mayo/research/koenig_lab/index.cfm.

The UBC event: <http://gels.ethics.ubc.ca:8213/ge3ls-arch/face-to-face>.

On deliberative democracy:
<http://www.deliberative-democracy.net>.

Faculty Publications

BOOK

Miles S. *Oath Betrayed: Torture, Medical Complicity and the War on Terror*. Random House, 2006. Issued in Arabic translation: Arab Scientific Publishers, Beirut, 2007.

ARTICLES

Elliott B., Gessert C., Peden-McAlpine C. Decision Making by Families of Older Adults with Advanced Cognitive Impairment: Spirituality and Meaning. *Journal of Gerontological Nursing* 2007;33(8):49-55.

Elliott C. Against Happiness. *Medicine, Health Care and Philosophy* 2007;10(2):167-171.

Elliott C. Guinea-Pigging. *The New Yorker* 2008:36-41.

Elliott C. Love in the Ruins. *BioSocieties* 2007;2(2):278-279.

Kahn J. Commentary: Informed Consent in Human Gene Transfer Clinical Trials. *Human Gene Therapy* 2008;19:7-8.

Continued on Page 8

Center for Bioethics will pilot “EthicShare” with a grant from the Andrew W. Mellon Foundation

EthicShare is part of a larger trend towards discipline-specific online communities that support the humanities, social sciences, and the sciences—all fields that play a role in practical ethics scholarship.

The University of Minnesota Center for Bioethics in partnership with the University of Minnesota Libraries and the Department of Computer Science has been awarded a \$517,000 grant from the Andrew W. Mellon Foundation to pilot “EthicShare,” an online website and database for ethics scholars and students to discover and share high quality digital articles and other materials—scholarly and popular press articles, multimedia objects, pre-prints, and archival documents.

Site users will be able to rate, comment on, and vet EthicShare content, allowing EthicShare to establish new forms of editorial control and community participation in the growth and future of the site. EthicShare marks the beginning of a new model of scholarship and collaboration in the community of applied ethics scholars.

share works in progress and collaborate on new ideas and the research that flows from them.”

The EthicShare pilot is a continuation of an earlier planning grant awarded to the University of Minnesota by the Council of Libraries and Information Resources with funds from the Mellon Foundation. EthicShare grows out of a planning partnership with Indiana University-Bloomington, Indiana University-Purdue University, Indianapolis, the University of Virginia, and Georgetown University. The pilot phase of EthicShare is bolstered by new relationships with the National Library of Medicine (NLM), the Council of Library and Information Resources (CLIR), Online Computer Library Center (OCLC), and others.

EthicShare is part of a larger trend towards discipline-specific online communities that support the humanities, social sciences, and the sciences—all fields that play a role in practical ethics scholarship. Recent priorities of American Council of Learned Societies, the National Institutes of Health, and the National Science Foundation, as well as the University of Minnesota, have included strategies to build community and support collaborative exchange among scholars distributed across the globe. The University of Minnesota is working to develop a sustainable online community for an evolving field with roots in the humanities, but with an impact found in a broad array of domains.

As a partnership between the Center for Bioethics, the Department of Computer Science, and the University Libraries, EthicShare is a unique interdisciplinary collaboration that brings together a diverse but deep commitment to innovation in the areas of information discovery, new forms of scholarship, and scholarly exchange and dissemination. Wendy Pradt Lougee, University Librarian, and computer science professor John Riedl, both co-principal investigators along with Professor Kahn, are leaders in the fields of digital library development, and social networking and collaborative filtering, respectively.

Together with Professor Kahn, Lougee and Riedl hope to develop an interdisciplinary virtual community for scholars that serves as a model for scholarly research for fields beyond practical ethics.

For more information see <http://www.lib.umn.edu/about/ethicshare/>.

“EthicShare is a groundbreaking opportunity for scholars to work together to create a powerful new approach to identifying and sharing the best materials in ethics—whether they are primary documents, government reports, or scholarly publications,” says Jeffrey Kahn, Director of the Center for Bioethics and one of the project’s principal investigators. “The technologies put to work in EthicShare will allow for detailed searching with far greater refinement than is currently available, including the ability to use reviews and quality ratings by colleagues as a way to find and select scholarly materials. In addition, EthicShare will create a way for scholars working in practical ethics to

Center News

Jeffrey Kahn, PhD, MPH, has been appointed to the National Ethics Committee for the March of Dimes.

Pan Flu project update—The Minnesota Department of Health (MDH) has extended its contract with the Minnesota Center for Health Care Ethics (MCHCE) and the University of Minnesota Center for Bioethics on the “Development of an Ethical Framework for Influenza Pandemic” project. Both Centers were contracted by MDH to assist with preparing to address critical ethical issues that are likely to arise during a severe influenza pandemic and to produce a set of ethical procedures for allocating medications, vaccines, protective equipment, and other health care and medical items that may be in short supply in a pandemic.

Five work groups and a protocol committee, in addition to the Resource Allocation Panel, have been meeting monthly as part of this project. It has become clear throughout the process that the framework cannot be fully developed without input from a broader segment of the population.

This extension of the project will insert a public engagement component that will occur between the preliminary recommendations from the Resource Allocation Panel and the final recommendations. The final framework will include the panel’s analysis of the community engagement findings and any necessary changes to the preliminary recommendations and final recommendations. See www.ahc.umn.edu/bioethics/research/influenza.html.

“In the Eye of the Beholder—Celebrating the Richness of Human Diversity”

Presented by Rick Guidotti, Founder, Positive Exposure

SAVE THE DATES

April 24, 2008: 7:00 pm - 9:30 pm, Illusion Theater, Minneapolis, MN

April 25, 2008: Noon - 1:30 pm, Mayo Auditorium, University of Minnesota, Twin Cities campus

Sponsors: University of Minnesota’s Institute for Human Genetics and the Center for Bioethics, and the Illusion Theatre.

Positive Exposure encourages participants to ask questions such as: What does a genetic disease look like? How do we define disability? How do we form our perceptions of disease and disability? What do others see when they see someone ‘affected’ with a disease or disability? These are among some of the most challenging questions students and practitioners in all areas of health care must face.

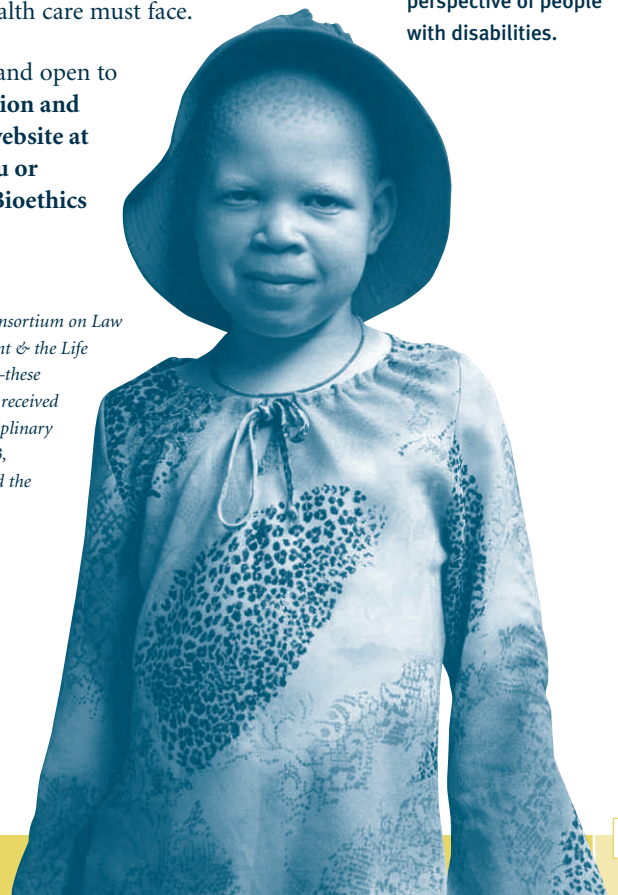
Both programs are free and open to the public. **For registration and information, visit the website at www.bioethics.umn.edu or contact the Center for Bioethics at 612-624-9440/email bioethx@umn.edu.**

Supported by a grant from the Consortium on Law and Values in Health, Environment & the Life Sciences, University of Minnesota—these grants are made possible by funds received through the Presidential Interdisciplinary Initiative Process. In October 2003, President Robert Bruininks named the Consortium one of 8 Presidential Interdisciplinary Initiatives.

“In the Eye of the Beholder” will focus on the unique perspective of people with disabilities.



“In the Eye of the Beholder” will focus on the unique perspective of people with disabilities. Each program will include a presentation, audience discussion, reception, and photograph exhibit by Rick Guidotti, founder of *Positive Exposure*—a non profit organization whose innovative programs challenge the stigma associated with difference and celebrates the richness of human diversity.



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 its annual seminar series. Seminars are held 12:15 to 1:30 pm on the University of Minnesota campus. For more information visit www.bioethics.umn.edu.

MAR 7

“Neither Common Nor Sense: Western Bioethics in Japan”, by Gregory Plotnikoff, MD, MTS, Faculty Associate, Center for Bioethics, University of Minnesota; Medical Director, Institute for Health and Healing, Abbott-Northwestern Hospital, Minneapolis, MN.

MAR 25

“Predictive Health Research Ethics,” by Eric Meslin, PhD, Director, Center for Bioethics; Assistant Dean

for Bioethics, School of Medicine; Professor of Medicine, Medical & Molecular Genetics and Philosophy, Indiana University, Indianapolis, IN.

MAY 9

Title to be announced, by Edward Ratner, MD, Assistant Professor, Department of Medicine, Division of General Medicine, University of Minnesota.

Center seminars have been designated to meet University of Minnesota Continuing Medical Education requirements. The University of Minnesota designates this educational activity for a maximum of 1 AMA PRA Category 1 Credit(s)[™]. Physicians should only claim credit commensurate with the extent of their participation in the activity.

Registration is required if you are attending for CME credit.

Invest in the Future - The Center for Bioethics Needs YOU

We live in an era of nearly constant innovation and advances in scientific and medical understanding. Although such advances have provided us with new ways of diagnosis and treatment unknown to previous generations, they have also created situations in which we face increasingly difficult questions that require complex analysis to help inform decisions.

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 issues of bioethics.

Faculty and staff in the Center for Bioethics address issues such as the medical profession's role in torture and capital punishment, end-of-life care, genetic testing and screening, and the ethics of cutting edge research. Their findings are shared in the classroom, published in books and articles, and through public presentations—all helping to inform and influence advances in research and public policy, and keeping important issues in the public arena.

Philanthropic support for the work of the Center and its faculty and staff are critical. Your tax-deductible gift will have a significant impact on those who continue important research, dialogue, discourse, and public engagement on issues of bioethics. For more

information contact Holly McDonough at the Minnesota Medical Foundation at 800-922-1663 or at h.mcdonough@mmf.umn.edu. Secure gifts may also be made on line at www.ahc.umn.edu/bioethics.

Visit the Center's website at www.bioethics.umn.edu for information on the following projects.

CURRENT RESEARCH

- Development of an Ethical Framework for Influenza Pandemic
- Ethics and Pharmaceutical Marketing
- Homelessness and End of Life
- Looking Into Practices of Gene Therapy Research
- Understanding Barriers to Living Donor Lung Transplantation

OVERVIEWS

- Human Stem Cells
- Ethics of Organ Transplantation
- New Frontiers in Genetic Testing and Screening
- Distributing Limited Healthcare Resources
- End of Life Care

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 issues of bioethics.

Calendar of Events

MAR 11

Carol Tauer, PhD, will speak on “Genetic Testing and Screening: What Are the Ethical Issues?” at York Senior Community, Edina MN. For information, call 952-841-9814.

MAR 26, APR 2, 9, 16, 23, 30

Center faculty will speak at the Osher Learning Institute (OLLI) University of Minnesota, Minneapolis, MN. For information, call 612-624-7847 or visit www.bioethics.umn.edu.

MAR 26

Maryam Valapour, MD, will speak on “Ethics of Organ Re-Transplantation” at the “Cutting Edge” Conference, University of Minnesota Children’s Hospital, Fairview & University of Minnesota Medical Center, Minneapolis, MN. For information, call 612-273-7272.

MAR 31

Jeffrey Kahn, PhD, MPH, will speak on “Stem Cell Therapies and the Ethics of Medicine on the Frontiers of Science” at OptumHealth, Scottsdale, AZ. For information, email bethany.blauer@optumhealth.com.

APR 4

John Song, MD, MPH, MAT, will speak on “Homelessness: Clinical and Ethical Challenges” at Providence Health Care Ethics Education Conference, Vancouver, BC Canada. For information, email fkoning@providencehealth.bc.ca.

APR 22 & 29, MAY 6

David Satin, MD, will speak on “Contemporary Issues in Bioethics” at the Complete Scholar Program, University of Minnesota, Minneapolis, MN. For information, call 612-624-4000.

APR 24

Jeffrey Kahn, PhD, MPH, will participate as a panelist on “A Changing World: Past and Present Threats to the Public’s Health” as part of the University of Minnesota’s commemoration of the Minnesota sesquicentennial, Minneapolis, MN. For information call 612-624-5100.

APR 24

David Satin, MD, will participate as a panelist at the Minnesota Health Care Roundtable, Minneapolis, MN. For information, visit www.mppub.com.

APR 24-25

University of Minnesota’s Institute for Human Genetics and Center for Bioethics present “In the Eye of the Beholder: Celebrating the Richness of Human Diversity.” For information see page 5 in this issue.

APR 30

Maryam Valapour, MD, will speak on “Moral, Ethical and Legal Issues in Critical Care” Division of Pulmonary and Critical Care Medicine conference, University of Minnesota, Minneapolis, MN. For information, call 612-624-9440.

APR 30-MAY 4

David Satin, MD, will speak on “Using Pay-for-Performance to Strengthen Medical Homes While Protecting Patient-Centered Care”; “Advanced Medical Ethics Skills for Residency Faculty: Improving Patient Care for the Present and Future”; and “Hospital Ethics Committee Resources for Family Medicine Faculty” at the 41st Annual Spring Conference of Society of Teachers of Family Medicine, Baltimore, MD. For information, visit www.stfm.org.

MAY 15

David Satin, MD, will speak on “Ethical Dilemmas Around Pay-for-Performance” at the “Family Medicine Update 2008” for the Department of Family Medicine and Community Health and Center for Spirituality and Healing, University of Minnesota. For information, visit www.stfm.org.

MAY 20

Jeffrey Kahn, PhD, MPH, will speak on “Incommensurable Views: How Should the Tensions Between a Utilitarian Approach to Science and Other Moral and Religious Belief Systems be Approached?” at “Science and the Citizen” conference, Salzburg, Austria. For information, email trust@21stcenturytrust.org.

MAY 21

Carol Tauer, PhD, will speak on “Bioethics and Stem Cell Research” at Irondale Senior High School, New Brighton, MN. For information, email Joe.Helm@moundviewschools.org.

JUN 9-12

Jeffrey Kahn, PhD, MPH, will speak on “Ethical Issues in Emerging Technologies” and “Models and Strategies for Implementing Ethics Instruction” at the 14th Annual Trainer-of-Trainers Conference “Teaching Survival Skills and Ethics” University of Pittsburgh, Snowmass, CO. For information, email survival@pitt.edu.

JUNE 24

Carol Tauer, PhD, will speak on “Forced Abandonment and Nursing Risk” at the Minnesota Nurses Association Ethics Committee Meeting, St. Paul, MN. For information, email lmash@mnnurses.org.

Center faculty will speak at the Osher Learning Institute (OLLI) University of Minnesota.



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The next 2008
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Faculty Publications *Continued from Page 3*

Kahn J, Wolf S. Understanding the Role of Genetics in Disability Insurance. *Journal of Law, Medicine & Ethics* 2007;Special Supplement 35(2):5-5.

McCarthy Veach P, **Bartels D**, LeRoy B. Coming Full Circle: A Reciprocal-Engagement Model of Genetic Counseling Practice. *Journal of Genetic Counseling* 2007;16(6):713-728.

Miles S. Human Rights, Abuses, Transparency, Impunity and the Web. *Torture* 2007;17(3):216-221.

Pirzadeh S, McCarthy Veach P, **Bartels D**, Kao J, LeRoy B. A National Survey of Genetic Counselors' Personal Values. *Journal of Genetic Counseling* 2007;16:763-773.

Plotnikoff G. Kampo Clinical Research in the United States: Challenges and Lessons. *Kampo Medicine* 2007;58;4:636-639.

Regan M, **Liaschenko J.** In the Mind of the Beholder: Hypothesized Effect of Intrapartum Nurses' Cognitive Frames of Childbirth Cesarean Section Rates. *Qualitative Health Research* 2007;17(5):612-624.

Song J, Bartels D, Ratner E, Alderton L, Hudson B, Ahluwalia J. Dying on the Streets: Homeless Persons' Concerns and Desires about End of Life Care. *Journal of General Internal Medicine* 2007;22:435-441.

Stein-Parbury J, **Liaschenko J.** Understanding Collaboration Between Nurses and Physicians as Knowledge at Work. *American Journal of Critical Care* 2007;16(5):470-477.

Valapour M. Living Donor Transplantation: The Perfect Balance of Public Oversight and Medical Responsibility. *The Journal of Clinical Ethics* 2007;18(1):18-20.

Wolf S, Kahn J, with input from the Working Group on Genetic Testing in Disability Insurance. Genetic Testing and the Future of Disability Insurance: Ethics, Law & Policy. *Journal of Law, Medicine & Ethics* 2007;Special Supplement 35(2):6-32.

Wolf S. Bioethics in Law Review. *The New England Journal of Medicine* 2007;357(4):426-427.

PUBLICATIONS

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