

# Bioethics Matters

A Newsletter for the Friends  
of Biomedical Ethics at UVA



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Visit our website at: <http://www.healthsystem.virginia.edu/internet/bioehums>

## Director's Letter

Each year, when the new school year begins and I've had to revamp my bioethics courses once again, I am reminded of how new the field is and how much it is still evolving. One of my courses is a bioethics internship, in various areas of the Medical Center, for students who are in their final year of UVA's stellar undergraduate bioethics program (led by Prof. John Arras, one of the Center's faculty affiliates). This semester is our 25<sup>th</sup> consecutive offering of that course and, as I look back over the syllabi since the first one in 1998, I'm struck by the evolution of the assigned readings, chosen to represent current interests and controversies in the field. Procedural essays about ethics consultation, published in standard bioethics journals, have

been gradually replaced by thoughtful commentaries on a multitude of themes, published in lay magazines like *The New Yorker* and *The Atlantic Monthly*.

This year, Center faculty have revived and revised our long-standing graduate course on the "foundations" of bioethics, offering it again for the first time since 2005. What's new in that course is that one can no longer offer a truly comprehensive survey of bioethics' history, methods, and foci without including sessions on organization ethics and global health ethics, as well as the expected discussions of clinical and research ethics. Thus this roughly 40-year-old discipline of bioethics moves into its next phase—what may be the end of its beginning—continuing to be what it has always aspired to be: a field of moral thought and practice that is both responsive to the actual lived questions arising in health care and responsible to those most affected by health care, that is, all of us in all places.

It is that spirit of aspiration and continuous evolution that we bring to our planning of the DSHEP conference, trying simultaneously to respond to your needs (including the time and money constraints of the current work economy) and to

challenge you with new material. Elsewhere in this newsletter you'll find an early draft of the March 2011 conference schedule. While noting that the agenda is not yet entirely settled, I draw your attention to one change which is certain: We will offer options for registration, allowing registrants to choose whether to focus on the first day's "basic" sessions—designed for persons new to ethics consultation and those who wish to refresh their knowledge and skills—or on the following days' more "advanced" presentations, or both. Throughout we will bring new issues to your attention, such as the change in Virginia law that makes "patient decision maker" committees necessary, and the moral challenges raised by the increasing number of our patients for whom spoken or written English is not an adequate means of conveying crucial information, or whose religious beliefs influence their choices in ways others find puzzling or troubling. These topics and others that will be part of the program are all areas in which there are not only many new things to be said, but also much for us to hear from you about your experiences and concerns. Plan now to join us! ♦

*Margaret Mohrmann*

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## Recent Faculty Publications/Presentations/Activities

### Donna Chen

#### Publications

+ Chen DT, Meschia JF, Worrall BB. Enrollment by surrogate authorization into stroke genetic research. *U.S. Neurology*, 2009;5(1):41-44.

#### Presentations

+ February 25, 2010. Informed Consent: Have We Gone Too Far or Not Far Enough? 2010 International Stroke Conference. San Diego, CA. (Invited speaker for juried, peer-reviewed panel).  
 + May 4, 2010. Empirical Ethics Research: A Complementary Approach or a Contradiction in Terms? Research Seminar. Center for Bioethics, Division of Public Health Sciences, Wake Forest University Health Sciences. Winston-Salem NC.  
 + May 26, 2010. Research Ethics and the Practicing Psychiatrist—The Brave New World of Research in One's Private Practice. New Orleans, LA. (Invited speaker for juried, peer-reviewed symposium panel: Advances in Psychiatric Ethics: New Approaches That Inform Psychiatric Practice.)

### Ann Mills

#### Publications

+Mills A, Tereskerz P. (2010) Empirical analysis of major stem cell patent litigation: The role of Universities. *Nature Biotechnology* 28(4): 325-328.  
 + Mills A, Tereskerz P. The Uncertain Future of Gene Patents. *Bioethics Forum*, the on-line arm of the Hastings Center Report. April 1, 2010 Available [http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4599&blogid=140&terms=Terkerz+and+%23filename+\\*.html](http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4599&blogid=140&terms=Terkerz+and+%23filename+*.html)

+ Mills A, Tereskerz, P. A Step in the Right Direction of Health Insurance Reform, *New England Journal of Medicine*, March 18, 2010, 362:11, first published in the on-line NEJM Health Care Reform Center available <http://healthcarereform.nejm.org/?p=3172&query=TOC>

#### Activities

+Reviewer for American Association for Bioethics and Humanities (2010) content area: Organization Ethics.

### Margaret Mohrman

#### Presentations

+April 15, 2010, First Annual Richard Gidney Seminar on Faith and Medicine, Keynote Address ("Spirituality and Medicine: A Healthy Partnership?") and Seminar Presentation ("Stories Matter"), Mt. Sinai Hospital and the Anglican Diocese of Toronto, CA.  
 + May 22, 2010, "Professing Medicine II," Commencement Address, University of Utah School of Medicine, Salt Lake City, UT.  
 + August 20, 2010, White Coat Ceremony Address, Eastern Virginia Medical School, Norfolk, VA.

### Lois Shephard

#### Presentations

+January, 2010, Panelist, "Health Care Reform" for the Culpeper Community Events Series, Culpeper VA.  
 + February, 2010, "End of Life Law and Ethics," Rotary Club. Charlottesville, VA.  
 + March, 2010, Moderator, presentation by Virginia Morris on "Our Parents, Our Selves, The Later Years." Institute on Aging, The Virginia Festival of the Book Charlottesville, VA  
 + March 2010, Moderator and Panelist (with husband), "Writers Under the Same Roof." The Virginia Festival of the Book Charlottesville, VA  
 + April, 2010, Moderator and Presenter (and co-organizer) Conference "Patient-Centered Law and Ethics," Wake Forest School of Law, Winston-Salem, NC. The two-day conference gathered an interdisciplinary group of scholars to consider

what a more patient-centered health law would look like and whether it would be worth pursuing. The report of that conference will appear in an upcoming issue of the *Wake Forest Law Review*.)

+ April, 2010 Guest Lecturer on "End-of-Life Law" at Wake Forest School of Law and at William and Mary Law School.

### Patti Tereskerz

#### Publications

+ Mills A, Tereskerz P. (2010) Empirical analysis of major stem cell patent litigation: The role of Universities. *Nature Biotechnology* 28(4): 325-328.  
 + Mills A, Tereskerz P. The Uncertain Future of Gene Patents. *Bioethics Forum*, the on-line arm of the Hastings Center Report. April 1, 2010 Available [http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4599&blogid=140&terms=Terkerz+and+%23filename+\\*.html](http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4599&blogid=140&terms=Terkerz+and+%23filename+*.html)  
 + Mills A, Tereskerz, P. A Step in the Right Direction of Health Insurance Reform, *New England Journal of Medicine*, March 18, 2010, 362:11, first published in the on-line NEJM Health Care Reform Center available <http://healthcarereform.nejm.org/?p=3172&query=TOC>  
 +Tereskerz, P. (2010) Data Safety Monitoring Boards: Legal and Ethical Considerations for Research Accountability. *Accountability in Research*, 17: 1, 30 – 50. ♦

## In the News:

### The Joint Commission Bars Discrimination on the basis of Sexual Orientation

Following President Obama's memorandum in April directing the Department of Health and Human Services to make rules that require all hospitals that receive federal Medicare and Medicaid funding – nearly every hospital in America – to protect the visitation and healthcare decision-making rights of lesbian, gay, bisexual and transgender patients (LGBT), (1) The Joint Commission has announced new and revised requirements to improve patient-provider communication applicable to the hospital accreditation program. (2)

RI.01.01.01, EP 11 states: The hospital provides care, treatment, and services free from discrimination related to age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression. (3) Moreover, the proposed requirement in Standard RI.02.01.01, EP 23 highlights the patient's right to unlimited access to a family member, friend, or other designated advocate for support. (4) RI.02.01.01, EP 23 states: EP 23. The hospital accommodates the patient's right to the presence of a family member, friend, or other designated advocate 24 hours a day, 7 days a week. Note: The hospital accommodates the patient's right to the presence of an advocate, unless this infringes on others' rights, safety, or is medically or therapeutically contraindicated. (5)

However, the Healthcare Equality Index which is an annual survey of healthcare policies and practices related to LGBT patients and their families, reports that more work needs to be done to

address these and related issues.(6) (The report relies on the responses from 178 healthcare facilities from 21 states and the District of Columbia. Thirteen healthcare networks submitted surveys covering a total of 141 network facilities. The balance of the data comes from 37 surveys representing individual, non-network facilities.) (7)

The data is shown below.

#### Percent of participants that answered "yes" to each criterion, if applicable: (8)

**1a** "Sexual Orientation" in Patients' Bill of Rights and/or Non-Discrimination Policy – 83.7%

**1b** "Gender Identity" in Patients' Bill of Rights and/or Non-Discrimination Policy – 29.2%

**2a** Equal Visitation Access for Same-Sex Couples – 31.8%

**2b** Equal Visitation Access for Same-Sex Parents – 32.3%

**3** LGBT Cultural Competency Training for Staff – 53.4% ♦

(1) <http://www.hrcbackstory.org/wp-content/uploads/2010/04/2010rightspatients-mem-final-rel.pdf>

(2) [http://www.hrc.org/documents/Joint\\_Commission\\_Perspectives\\_January\\_2010.pdf](http://www.hrc.org/documents/Joint_Commission_Perspectives_January_2010.pdf)

(3) <http://www.jointcommission.org/NR/rdoonlyres/D44C4DE4-F5CD-4116-84AF-D5B3E8D4E94F/0/PDF1HAPPProposedRequirements.pdf> at page 6.

(4) Id at page 5.

(5) Id.

(6) [http://www.hrc.org/documents/HRC-Healthcare-Equality-Index\\_2010.pdf](http://www.hrc.org/documents/HRC-Healthcare-Equality-Index_2010.pdf)

(7) Id at page 6.

(8) Id at page 7.

#### Decision on the BRAC1 and BRAC2 patents

Mills and Tereskerz

Last issue, we reported on the case, *Association for Molecular Pathology, et al., Plaintiffs, v. United States Patent and Trademark Office, et al.*, in which the plaintiffs argued that that patents on the genes BRCA1 and

BRCA2 are illegal and restrict both scientific research and patients' access to medical care. The plaintiffs contended that patents on human genes are unconstitutional "because they cover products of nature, laws of nature and/or natural phenomena, and abstract ideas or basic human knowledge or thought." (1)

On March 29, the court invalidated seven of Myriad's 23 patents associated with the genes. The decision was based on the ground that these patents had been "improperly granted" – that an isolated and purified version of the gene is nothing more than a "lawyer's trick" that circumvents the prohibitions on the direct patenting of the DNA in our bodies but which, in practice, reaches the same result." (2)

Not surprisingly, the decision will cause turmoil in industries associated with gene patenting. Although it is possible that the decision will be overturned on appeal, a multitude of questions require thoughtful examination. (3) These questions include, among others whether or not venture capitalists will continue to fund those segments of the biotechnology industry interested in identifying and creating tests and therapeutics associated with genes, how the path of commercialization will change, and how the path of research is affected.

Not surprisingly, we suspect that one way or another, these genes will be back in the news.

(1) *Association for Molecular Pathology, et al., Plaintiffs, v. United States Patent and Trademark Office, et al.*, Defendants. No. 09 Civ. 4515.

(2) Id.

(3) Mills A, Tereskerz P. The Uncertain Future of Gene Patents. Bioethics Forum, the on-line arm of the Hastings Center Report. 04/01/2010 Available [http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4599&blogid=140&terms=Terreskerz+and+%23filename+\\*.html](http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4599&blogid=140&terms=Terreskerz+and+%23filename+*.html) ♦

## *Ethics Conundrums: Research from Center Scholars*

Readers of Bioethics Matters should be aware of two recent publications and one “white” paper by Center faculty. The first publication is Lois Shepherd’s thoughtful essay, “Asking Too Much: Autonomy and Responsibility at the End of Life.”(1) In the essay, Lois describes four cases in which she argues that not only are there limits to patient autonomy, there are circumstances in which individuals have no right to demand that providers (professional and/or family members) honor their wishes. Moreover, she insists that in these cases--where individuals ask others to deny their own humane responsibilities--individuals have a *duty* not to make these demands.

The second is Patti Tereskerz’s essay, “Data Safety Monitoring Boards: Legal and Ethical Considerations for Research Accountability. (2) In the essay, Patti outlines reasons why members of Data Safety Monitoring Boards (DSMBs) can and will be sued. She argues that although the risk of being sued exists, “...it will likely prove difficult to prove liability against DSMBs and their members, except in the case where there is violation of a regulation or policy, given the lack of uniform practice standards in how DSMBs should be structured and managed.” Nevertheless, as Patti points out, just being named in a lawsuit of this sort can be financially devastating as well as a public relations nightmare for an institution affiliated with a DSMB member who is being sued. She offers practical advice to those considering serving on a DSMB in the hope that qualified persons will not be dissuaded from serving on these important monitoring mechanisms.

A white paper written by Lois may also be of interest to our readers. The paper, entitled “Rationing Health Care at the End of Life” was written for the Miller Center for Public Affairs at the University of Virginia and is available at <http://millercenter.org/public/debates/life>. In the paper, Lois, gives a snap shot of the costs associated with end of life care, she outlines the various arguments, pro and con, of rationing health care at the end of life, and offers resources for people wanting to read further. This comprehensive and balanced essay will be of interest to anyone interested in the debate that we currently have ,and which we will surely continue, as we, as a society, seek to manage our healthcare dollars in more efficient and effective ways.

(1) Shepherd, L. Essay: Asking Too Much: Autonomy and Responsibility at the End of Life. 26 J. Contemp. Health L. & Pol'y 72

(2) Tereskerz, Patricia M.(2010) 'Data Safety Monitoring Boards: Legal and Ethical Considerations for Research Accountability', *Accountability in Research*, 17: 1, 30 — 50



## DSHEP–2011

The Center for Biomedical Ethics in cooperation with Continuing Medical Education (UVA) is pleased to offer its annual program, “**Developing Skills for Healthcare Ethics Programs.**” The program will be held from March 16<sup>th</sup> to 18<sup>th</sup>, 2011, in the Jordan Hall Conference Center at the University of Virginia. Faculty will include members of the UVA Center for Biomedical Ethics and Humanities and the UVA Ethics Consultation Service, plus ethics leaders from other healthcare institutions.

The agenda for the program is being constructed in two related segments, offering participants the choice to attend one or both sessions. The first day of the conference is designed for participants who are beginning their efforts on ethics programs or who want to refresh their knowledge and skills. The sessions in this segment highlight ethical theories behind clinical ethics consultation, cover various important aspects of ethics programs’ functioning, and offer practical advice on running an ethics program or consultation service.

The second segment is designed for participants who wish to go further in developing their ability to contribute to their ethics programs and/or clinical ethics services. This one-and-a-half day long component introduces and explores both new and enduring controversies. The 2011 program will include examinations of integrity, encouraging participants to reflect on what integrity means personally and to their ethics programs, and the related phenomenon of “moral distress,” as well as on-going issues surrounding the concept of futility, moral aspects of care of persons with disorders of consciousness, and institutional experiences with religious diversity. We shall also explore with you the nuances of healthcare reform and how the changes may affect ethics services. For more information, please contact Carrie Gumm at [cg2b@virginia.edu](mailto:cg2b@virginia.edu), or 434-924-5695. ♦

**Questions, comments  
and items of interest**  
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## BIOETHICS MATTERS

*The Center for Biomedical Ethics  
and Humanities*



**DSHEP 2011 – Draft Schedule**  
**March 16<sup>th</sup>- 18<sup>th</sup>, 2011**  
**WEDNESDAY, March 16th**

- 8:00 -8:30 Welcome, Introductions
- 8:30-10:30 Defining Morality and Ethics in Ethics Consultation
- 10:30-10:45 Break
- 10:45-11:45 Ethics Committee Work—Policies, Patient Decision Makers Sub-Committee
- 11:45-12:30 Box lunch
- 12:30-1:30 Medical Center Hour
- 1:45 – 2:45 Running an Ethics Consult Service
- 2:45-3:00 Break
- 3:00-4:00 Running an Ethics Consult Service (continued)
- 4:00-5:00 Cases

**THURSDAY, March 17th**

- 8:00-8:30 Welcome, Intros PRN, Reflection on Wednesday’s Content
- 8:30-9:30 Integrity
- 9:30-9:45 Break
- 9:45-11:45 Moral Distress
- 11:45-1:00 Box lunch
- 1:00-3:00 Surrogate Decision Making; Futility Policies
- 3:00-3:15 Break
- 3:15-4:45 Disorders of Consciousness

**FRIDAY, March 18th**

- 8:00-8:30 Reflection on Thursday’s Content
- 8:30-9:30 Religious Diversity
- 9:30-10:30 Language Diversity/Translators
- 10:30-10:45 Break
- 10:45-11:45 Implications of Health Care Reform
- 11:45-12:00 Final reflections
- 12:00 ADJOURN
-