

Bioethics Matters:

*A Newsletter for the Friends of the
Center for Biomedical Ethics*



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from the Director:

Acting at the request of the scientific community and citing a lack of government leadership, the National Academies of Science (NAS) proposed ethical guidelines for research with human embryonic stem cells in a report released in April called "Guidelines for Human Embryonic Stem Cell Research." These guidelines are voluntary but the NAS hopes that they will be accepted in the private and public sectors. The NAS also expects the report to influence the debate in Congress, where some lawmakers wish to allow new human stem cell lines to be derived and other lawmakers are seeking tighter restrictions. The guidelines were drawn up by a committee led by Dr. Richard O. Hynes of the Massachusetts Institute of Technology and Dr. Jonathan D. Moreno of the University of Virginia.

Below is the Preface of the report. The full report can be found at www.nas.edu.

Preface

We are pleased to offer our committee's report on guidelines for human embryonic stem cell research. This report and its recommendations are the result of many hours of committee meetings as well as a public workshop. During those sessions we heard from many dedicated and talented people who represent a wide range of views. We have tried to take these diverse perspectives into account in a report that mirrors the seriousness with which we have reflected upon them. Our task was made more difficult and also more significant by events in the worlds of science and public affairs, which altered the terrain even as we explored it. All of us on the committee have appreciated the opportunity to be part of this important and timely effort.

Great possibilities for improvements in human health are offered by research

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CBE ANNOUNCES NEW PROGRAM

Jonathan Moreno, Ph.D., Director of the Center for Biomedical Ethics, is pleased to announce the formation of the Program for Ethics in Healthcare Systems, which will be devoted to undertaking research and providing education and policy guidance. The Program will provide policy recommendations based on its research findings concerning the interactions among the drug/device industry, and the *legal and regulatory, education, research, and clinical practice* (health care delivery) environments. To our knowledge, *no* non-industry supported entities have undertaken this mission. A distinguishing feature of the Program will be its systemic approach in considering the impact and interactions of such relationships. We foresee that the Program will become a national leader in health policy relied upon by the scientific and biomedical ethics communities as well as legislative and regulatory agencies. Establishing the Program represents a natural progression of the Center's work in the areas of research ethics, financial conflicts of interest, and organizational and system ethics. The Center

staff has an established publication record as well as NIH and foundation supported research underway in these areas. In addition, several other grant proposals are currently under consideration.

Patti Tereskerz J.D., Ph.D. will serve as Director of the program and Ann Mills, M.sc.(Econ), M.B.A. will serve as Co-Director. The program is being supported by Arthur Garson, M.D., Dean of the Medical School of the University of Virginia. For further information please contact Patti at pjm7s@virginia.edu or (434-243 6659) or Ann Mills at amh2r@virginia.edu or 434-982 3978.



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CALENDAR

Developing Skills for Hospital Ethics Programs March 1-3, 2006
Charlottesville, VA

The New Medicine: The Ethics and Policy of Regenerative and Replacement Therapies March 16-17, 2006
Charlottesville, Virginia.

For details, please call (434) 924-5974 or write the Center at the address opposite or visit our website at the address above. ◆

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Questions, comments and items of interest should be sent to: Ann Mills, Editor, Bioethics Matters, PO Box 800758, HSC, Charlottesville, VA 22908 or call (434) 982-3978 or e-mail amh2r@virginia.edu

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CENTER PUBLICATIONS and SELECTED ACTIVITIES

Paul Lombardo

In October, Professor Lombardo was a visiting professor at Aga Khan University Karachi, Pakistan, where he spoke at the 2nd Annual Symposium on Clinical Ethics.

While in Karachi, he gave the Inaugural Lecture at the Sind Institute of Transplantation Centre for Bioethics and Culture. He delivered visiting lectures at ten universities this year, including the University of Pennsylvania, Washington University (St. Louis), Queens University (Kingston Canada) and Northwestern University, and he also spoke at the annual meetings of the American Society of Bioethics and Humanities, the American Association for the History of Medicine, and the American Society of Law, Medicine and Ethics Health Law Teachers Conference.

In addition to participating on study sections at the National Institute for Mental Health, the National Library of Medicine, and the National Institute of Dental and Craniofacial Research, he was recently named to an NIH working group on gene transfer to treat Sickle Cell and Cooley's Anemia.

Publications

Paul Lombardo. A Tribute to John C. Fletcher 32 Journal of Law Medicine & Ethics (Fall, 2004) 538-539.

Ann Mills

Publications

M.V. Rorty, P.H. Werhane, Ann E. Mills, "The Rashomon Effect: Justifying a Systems Approach to Ethics in Health Care," HEC Forum 16(2)1-20 2004.

Ann E. Mills and Edward M. Spencer, Values Based Decision-Making: A Tool for Achieving the Goals of Healthcare Organizations, HEC Forum 17 (1)18-22 2005.

A. E. Mills, P. Tereskerz, W. Davis, "Is Evaluating the Ethics Consultation on the Basis of Cost a Good Idea?" Cambridge

Quarterly of Health Care Ethics. 14(1) Winter 2005 p. 54-66

Ann E. Mills and P.H. Werhane, "Organization Moral Distress", in The Blackwell Guide to Encyclopedia of Management (2nd edition) MA: Blackwell Publishing 2005 p.391-394

Presentations

"Business Practices and Professionalism," American Association of Applied Ethics, San Antonio, TX February 2005.

Jonathan Moreno

Appointments:

Co-Chair Committee on "Guidelines for Human Embryonic Stem Cell Research," National Academy of Sciences/Institute of Medicine, Washington, DC, April 26, 2005.

Appointed to Institute of Medicine Committee on Ethical Considerations for Revisions to DHHS Regulations for Protection of Prisoners Involved in Research, Spring 2005.

Publications:

Moreno J.D. "Secret State Experiments and Medical Ethics." In: A.W. Galston and C.Z. Peppard, eds, Expanding Horizons in Bioethics. Dordrecht, The Netherlands: Springer, 2005.

Reitsma A.R. and Moreno J.D. Ethics of Innovative Surgery: Surgeons: Definitions, Knowledge, and Attitudes. Journal of the American College of Surgeons 2005(1), 103-110.

Guyer R.L. and Moreno J.D., Slouching Toward Policy: Lazy Bioethics and the Perils of Science Fiction. The American Journal of Bioethics 4(4):W14, 2004.

Moreno J.D. The End of the Great Bioethics Compromise. Hastings Center Report 35 (1):14015, 2005.

Moreno J.D.
DARPA On Your

CONFERENCES

The Center for Biomedical Ethics, in cooperation with Continuing Medical Education (UVA), is pleased to announce a new program, "**Developing Skills for Hospital Ethics Programs.**" The program will be held from March 1-3, 2006 in Jordan Hall at the University of Virginia.

This three day advanced program is intended to introduce different models of ethics programs, differing models of services ethics programs provide, as well as enhancing the skills of those institutional representatives already serving on ethics programs. In addition, it will supply tools to participants interested in identifying areas in the institution where ethics programs might con-

For information on conference activities please contact, Carrie Gumm, Center for Biomedical Ethics, (434) 924-5695; or e-mail her at cg2b@virginia.edu

sider enlarging their role. **Program registrants are expected to have already obtained the basic education expected of most ethics committee members.** Faculty will include members of the UVA ethics program, the UVA Ethics Consultation Service, as well members of ethics programs from other institutions.

Program registration will be limited so registrants are able to fully interact with colleagues and faculty. The cost of the program is \$650 per registrant. The fee includes breakfasts, lunches, CMEs or CEUs, and conference materials. ♦

The New Medicine: The Ethics and Policy of Regenerative and Replacement Therapies *SEE ETHICS CONUN-*

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ETHICAL CONUNDRUMS: The New Medicine: The Ethics and Policy of Regenerative and Replacement Therapies

The New Medicine: The Ethics and Policy of Regenerative and Replacement Therapies

The Program for Ethics in Health Care Systems in the Center for Biomedical Ethics, in collaboration with the Islet Cell Transplant Center, the Morphogenesis and Regenerative Medicine Institute and supported by the Office of the Provost and Vice President for Research, is pleased to announce a national conference, "The New Medicine: The Ethics and Policy of Regenerative and Replacement Therapies," will be held March 16-17, 2006, at the Boar's Head Inn. The program will explore medical, financial, ethical, and policy implications of the new medicine (stem cell research and living donor transplantation).

The first day's discussion will center on stem cell research and will address topics including *Reviewing Adult and ES Cell Science, Policy and the NAS/IOM Committee, The California Experience, Financing the New Medicine (Profits, Non-Profits, Government, Industry, and Private), Regulation and Oversight, and Patients' Perspective*. The second day will center on issues concerning living donor transplant surgery and will include topics such as *History of Living Donors, Overview of Science, Ethics & Policy, UNOS – Bridging the Shortfall, and The Federal Role*.

The program, which will include nationally known experts as faculty, is intended for institutional leaders in the research environment from both the private and public sectors, representatives from regulatory agencies, patient advocacy groups, and others associated with policy making, research and health care delivery, including scientists, physicians, and other clinicians.

The program is intended to provide participants with an understanding of the medical, ethical and policy issues involved in the conduct of human embryonic stem cell research and living donor transplant surgery.

The program fee of \$300 (supported by the Office of the Provost and Vice President for Research) includes continental breakfasts, lunches, reception and dinner and materials.



For further information, or to register or to obtain a brochure, please contact Carrie Gumm, Program Administer, at (434 924-5695) or e-mail her at cg2b@virginia.edu. ♦

Director's Letter...continued

using human stem cells, both adult and embryonic. Like many scientific advances, these technologies raise questions about balancing the evident promise against the potential for inappropriate application. In the case of embryonic stem cell research, there are differing opinions within our society about the relative merits and risks of various approaches and there are philosophical differences about what is or is not appropriate.

Some believe strongly that we should not turn away from the promise that embryonic stem cells will provide new therapeutic advances. Others believe that the derivation and application of human embryonic stem cells will undermine the dignity of human life. These disparate views are deeply and sincerely held and must be considered as we move forward in advancing this research. Some of the qualms arise from unfamiliarity and the shock of the new, but others arise from concerns about the nature of human life, about ethical treatment of reproductive materials and about exploitation of donors of such materials. Those ethical concerns need to be balanced against the duty to provide the best medical care possible, enhancing the quality of life and alleviating suffering for many people. The challenge to our society is to achieve that balance.

Scientific inquiry should not proceed unfettered, without consideration for the ethical and public policy imperatives of the society in which it operates. On the other hand, concerns about potential ethical complexities should be cause for judicious oversight and regulation, not necessarily for prohibition. Our democratic society should be capable of entertaining challenges to familiar beliefs and adapting to new conditions without yielding on its fundamental values. We believe that it is possible to do so, that human dignity will be enhanced, rather than diminished, by the great project of addressing

Director's Letter...continued

the suffering that attends illness. Freedom of inquiry and a confident attitude toward the future are at the heart of American civic philosophy, in which the freedom to explore controversial ideas is celebrated rather than suppressed. That is one reason that our country's scientific establishment is the envy of the world, a source of our inventive energy that was celebrated by Thomas Jefferson who wrote, "Liberty is the great parent of science and of virtue; and a nation will be great in both in proportion as it is free."

In that spirit we offer this report.

Richard O. Hynes
Jonathan D. Moreno

Co-chairs, Committee on Guidelines for Human Embryonic Stem Cell Research



Activitiescontinued

Mind. Cerebrum 6(3):91-99, 2004.

Review of Vaccine A: The Covert Government Experiment That's Killing Our Soldiers -- and Why GI's Are Only the First Victims, by Gary Matsumoto. In: Washington Post Book World, November 7, 2004, BW05.

Presentations

Since October 2004 Moreno has given presentations to four universities, Yale, University of Texas, Harvard Medical School and Emory University. In addition, he has given talks to The American Association of Human Research Protection Programs, the Center for Practical Bioethics in Kansas City, the Workshop on Human Embryonic Stem Cell Research, National Academy of Sciences in Irvine California, the Conference on the 40th Anniversary of the Declaration of Helsinki in Hanover, Germany, and in April, he spoke at the

Activities...continued

Centre for Biomedical Ethics and Culture, Sindh Institute of Urology and Transplantation, in Karachi, Pakistan.



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