President Bush’s long awaited decision on federal funding for stem cell research has a little for everybody but completely satisfies no one. By limiting research funding to some 60-odd existing stem cell lines (or colonies), did the president stake out a clear moral position or merely craft a political compromise? Whatever the answer, there are important implications for the future of research on embryonic stem cells.

The president tried hard in his primetime speech to emphasize his commitment to protecting what he described as the future lives represented by human embryos. But at the same time he acknowledged the potentially lifesaving medical breakthroughs offered by embryonic stem cell research. To get the best of both worlds, the president laid out a position that allows funding of stem cell research so long as the cell lines used were created before August 9, 2001, since in the case of the 64 embryos destroyed to create those cell lines, he argued that the “life and death decision has already been taken.”

Unfortunately, to rely on the fact that the 64 cell lines were already derived is to introduce a distinction without a difference. Even under the limited research uses outlined by President Bush, the administration still has a problem with “dirty hands”—public monies will be spent on research that required and relied on the destruction of embryos.

The president made clear that his policy means that no new embryos would be harmed, but his stated...
These disparities raise a number of ethical issues. First, is dying out of the hospital by choice or related to access to hospital care? A number of studies have shown that a substantial majority of individuals with serious illness would prefer to die at home, despite access to emergency medical services and hospital care across Minnesota. It appears that dying at home is by choice, but that some deaths occur in hospitals and nursing homes despite patient preferences. Instead of problems with access to hospital care, the pattern of small area geographic disparities in rates of death at home suggest that there are regions with limited access to home-based care. This raises ethical issues regarding community allocation of resources to different types of health services, and how we must balance the needs for intensive care units versus home hospice services.

A second set of issues involves the nature of the relationship between health care providers and patients, particularly in the home setting. In the hospital, the health care team, led by the physicians, is clearly “in charge.” At home, the patient and family are in charge. Health care providers can act as advisors, teachers, and coaches, but the decision to follow a care plan is generally in the hands of the patient and family. This dynamic creates a number of ethical dilemmas for clinicians.

The most obvious challenge is refusal of care. Dying patients at home are free to not only refuse to follow advice given by health professionals, but they can refuse to even visit the doctor or allow entry to a visiting nurse. This creates an ethical challenge for the professional who may have difficulty accepting the notion of a right to refuse health care when it is not possible to assess the patient’s decision making capacity.

For patients who want care, but can’t get to the doctor’s office due to infirmity, does the doctor have an obligation to go to the patient’s home? Is it abandonment to require that a dying patient who wants medical care come to the office or be admitted to the hospital? If the doctor is willing to make a housecall, as many doctors do occasionally, how far must a physician be willing to travel? Should nurses accept the absence of the doctor near the end of life at home, when hospital care for the same illness is associated with daily physician visits? These questions, rarely addressed in the traditional hospital-based biomedical ethics literature, are everyday problems in home-based end of life care.

Finally, clinicians in home-based end of life care face serious challenges related to medications, particularly opioids and similar drugs. In the home setting, patients may take (or have administered to them) more or less than prescribed doses of controlled substances. In extreme cases, patients or caregivers may choose to use prescribed medications to intentionally hasten death. Clinicians must decide whether to allow access to enough medication to make such a choice possible. The alternative risk is that the patient may not have enough medication on hand to manage symptoms adequately. This is a far more common though equally complex issue as the well-analyzed but rare problem of a request for directly administered physician assisted suicide.

Most people who are asked express a preference for end of life care at home, and dying outside of the hospital has become common. But the home setting at the end of life raises a set of unique, complex, and challenging ethical issues that are rarely addressed by hospital-based ethics. The paucity of discussion of these issues may contribute to the ongoing disparity between patient preference for home based end of life care, and the predominant model of nursing home and hospital care for the dying in our community.

References


Faculty Profile
Edward Ratner, MD

Edward Ratner has a faculty appointment in the Department of Internal Medicine with a secondary appointment in the Department of Family Practice and Community Health, University of Minnesota Medical School. Originally from the Twin Cities, his medical training began at the University of Chicago and its affiliate hospitals. He subsequently trained at Harvard’s Geriatric Education Center, the Home Medicine Program at Boston University, and in the University of Minnesota’s Internal Medicine Geriatric Fellowship. He is also a graduate of the National Library of Medicine Medical Informatics Fellowship program. He has been practicing Geriatric Medicine for the past 15 years, in the clinic, hospital, nursing home, and in home care. He has led programs on end of life care for Allina Health System, and for the Minnesota Partnership to Improve End of Life Care. Dr. Ratner currently serves as a member of the Minnesota Commission to Improve End of Life Care; as Medical Director for Heartland Home Health Care and Hospice; and as President of the American Academy of Home Care Physicians.

Selected Publications

ARTICLES

Center News

Faculty & Associates

Muriel Bebeau, PhD, has been appointed to The National Academy of Sciences: Institute of Medicine 2001-2002 Committee on Assessing Integrity in Research Environments.

Steven Miles, MD, was awarded a grant by the National Institutes of Health for a conference on “African-American Genealogy: Old Records and New Genetics.” The conference will be held on June 21 and 22, 2002 on the University of Minnesota campus. For more information, contact the Center.

Edward Ratner, MD, has been appointed to the faculty in the Section of General Medicine, Department of Medicine, University of Minnesota Medical School.

Susan M. Wolf, JD, has been named the David Barap Brin Visiting Professor in Medical Ethics for 2002 at Johns Hopkins University School of Medicine. She will be in residence February 14-15, 2002.
justification for limited funding seems to support going further. If stem cell research is justified by the combination of great potential therapeutic benefit and a prior decision about the fate of the embryos used in the research, then a particular date holds no magic as a cut-off. There are conservatively estimated to be some 200,000 frozen embryos stored around the world, all awaiting decisions about what should be done with them. Many of them will be discarded, and so under the president’s logic, so long as “the life and death decision” to discard those embryos has already been made, they could justifiably be used for stem cell research.

Part of the problem with settling on use of existing cell lines is that since they were all created with private monies, the companies that funded their creation have ownership claims that may extend to not only the cells but to the results of research employing them as well. Licensing agreements to address these issues are in the works, with the hope that they won’t require eating into some of the $250 million the president announced would be devoted to stem cell research this year.

Even if access to existing stem cells can be assured, very few scientists think the 64 cell lines will be enough to satisfy the range of embryonic stem cell research likely to be pursued, whether because the cell lines won’t continue dividing, lack the ability to differentiate into all the needed cell types, or don’t have the desired genetic characteristics. The Bush administration has suggested that the private sector should step in if research requires the use of existing or created embryos. This would avoid federal funds being spent on ethically contentious research, but in the process will push such research outside the reach of government control and oversight as well as away from public scrutiny—just the opposite of what controversial research deserves.

In the end, this is a decision born of political compromise but cloaked in ethical argument. Limiting research to a few cell lines is less than scientists hope for, but may be all the Bush Administration can muster, as they find themselves caught choosing between dirty hands and falling behind in an increasingly important area of research. It may be that demands for a more flexible research environment and the promise of new cures could tip the balance, but that decision has been put off for another day.

A version of this article appeared in Dr. Kahn’s column “Ethics Matters” which appears bi-weekly on CNN.com/health.

Positions Available

Post-Doctoral Fellowship

The Center for Bioethics at the University of Minnesota will have a one year post-doctoral fellowship available to begin in July 2002. The goal of the fellowship is to foster scholarship and career advancement in the field of bioethics. The award will be $27,000 plus health care coverage for the fellow and a partial subsidy for the fellow’s dependents.

Applications must be submitted by February 15, 2002. For information and applications, contact the Center for Bioethics, at 612-624-9440, fax 612-624-9108, or e-mail: howar025@tc.umn.edu.

Clinical Ethics Fellowship

The University of Texas MD Anderson Cancer Center invites applications for a full-time, one-year, renewable Fellowship in Clinical Ethics. Deadline for applications is February 1. For more information, visit http://www.mdanderson.org/DEPARTMENTS/clinical ethics/ or contact: The Clinical Ethics Service, The University of Texas MD Anderson Cancer Center. Telephone: 713-792-8775, Fax: 713-745-0674, or Email: vsalleyh@mdanderson.org
February 26, 2002

This day-long national conference will explore the legal, ethical, and clinical implications of pharmacogenomics. Sponsored by the Consortium on Law and Values in Health, Environment & the Life Sciences, the Joint Degree Program in Law, Health & the Life Sciences, the Center for Bioethics, College of Pharmacy, MD/PhD Program, and Department of Pharmacology, University of Minnesota. The conference will be held at Cowles Auditorium, Hubert H. Humphrey Center, University of Minnesota West Bank campus.

For more information, call 612-625-0055.

PHARMACOGENOMICS
THE Legal, Ethical, AND Clinical Challenges
UNIVERSITY OF MINNESOTA

Faegre & Benson Lecture Series on Law, Health & the Life Sciences

The Consortium on Law and Values in Health, Environment & the Life Sciences and Joint Degree Program in Law and Values in Health, Environment & the Life Sciences, University of Minnesota, present the following events. All lectures will be held from 11:30 am – 1:00 pm, Room 25, Walter F. Mondale Hall, University of Minnesota Law School.

Oct 10
“Regulating Reproduction, Replication & Research: Governing IVF, Stem Cells, Cloning & Germline Genetics” by George Annas, JD, MPH, Boston University Faculty Commentators: Professor Ken Keller, Humphrey Institute, and Professor John Wagner, Stem Cell Institute

Nov 28
Discussion on the stem cell debate by Lori Andrews, JD, Chicago-Kent School of Law Faculty Commentators: Professor Jeffrey Kahn, Center for Bioethics, and Professor Catherine Verfaillie, Stem Cell Institute

Apr 10
“Cloning and Other Monkey Business” by Don Wolf, PhD, Oregon Health Sciences University and Oregon Regional Primate Research Center Faculty Commentators: Professor Susan M. Wolf, Law School, and Professor Christopher De Jonge, Reproductive Medicine Center

Lunch Series on the Societal Implications of the Life Sciences will be held from 12:15 - 1:15 pm, in the William G. Shepherd Room, Federick R. Weisman Art Museum.

Dec 13
“Stem Cells, Cloning, and Genetic Choice in Reproduction” by John Robertson, JD, University of Texas School of Law

Jan 24
“From Laboratory to Clinic: Issues in the Oversight of Innovative Reproductive Technologies” by Andrea Bonnicksen, PhD, Northern Illinois University

Mar 14
“Human Molecular Genetics and the Subject of Race: Contrasting Theory and Rhetoric with Practical Applications in Law and Medicine” by Troy Duster, University of California, Berkeley

For more information on these seminars, contact Ann Hagen at 612-625-0055 or lawvalue@umn.edu.
Recent Faculty Publications

Books


Articles


Center Publications

Reading Packets

Center packets contain an overview of legal and ethical issues, key articles, and a bibliography.

No. 1: Organ Transplantation (August 1997)

No. 2: Withholding or Withdrawing Artificial Nutrition and Hydration (July 1997)

No. 3: Termination of Treatment of Adults (September 1997)

No. 5: Distributing Limited Health Care Resources (April 1997)

No. 6: Resuscitation Decisions (June 1997)

No. 7: The Determination of Death (May 1997)

No. 8: New Frontiers in Genetic Testing and Screening (August 1999)

Annotated Bibliography

- Ethical Issues in Managed Care (1997) — articles addressing ethical issues in managed care.

Reading packets are available for $5 each. All orders must be prepaid. To order reading packets or reports, make checks payable and mail to:

Center for Bioethics
University of Minnesota
N504 Boynton
410 Church Street SE
Minneapolis, MN 55455-0346

Visit the Center’s Resource Center at N504 Boynton, 410 Church Street SE, Minneapolis, MN or online at www.bioethics.umn.edu.
**Calendar of Events**

**Oct 11-14**  
Carl Elliott, MD, PhD, will give a plenary address at the Canadian Bioethics Association Annual Meeting, Winnipeg, Manitoba. Susan Parry will present a paper on “Narrative Bioethics: Literature and Personal Memoirs,” and Josie Johnston will present a paper on “If Thy Leg Offend Thee, Cut it Off.” For information, call 204-235-3619.

**Oct 12**  
“Professional Ethics in Health Care and Beyond” conference sponsored by the Minnesota State University at Mankato. Debra DeBruin, PhD, will speak on research ethics, and Joan Liaschenko, RN, PhD, will be the keynote speaker on “Health Care Ethics in Day-to-Day Practice,” and on “Ethical Issues in Genetics and Health Care.” For information, call 507-389-2077.

**Oct 14-19**  
Jeffrey Kahn, PhD, MPH, will be part of the faculty for the week-long seminar “Biotechnology—Ethical, Legal and Social Issues,” at the Salzburg Seminar, Salzburg, Austria. For information, visit website: www.salzburgseminar.org.

**Oct 18**  
Susan M. Wolf, JD, will lecture at St. Louis University School of Law in the Distinguished Speakers Series. For information, call 314-977-3995.

**Oct 21-23**  
Jeffrey Kahn, PhD, MPH, will speak on “Conflict of Interest in Research in the US,” at the Sino-US Conference on the Protection of Human Subjects in Clinical Trials and Biomedical Research. Sponsored by the Office of International Cooperation, Peking University Health Science Center, Kunming, China. For information, email: dstern@med.umich.edu.

**Oct 24**  
Jeffrey Kahn, PhD, MPH, will speak on “Ethics of Allocation: Should We Ration?” at a conference on Transplant Immunosuppression 2001: The Compleat Care of the Transplant Recipient, sponsored by the University of Minnesota Medical School. For information, call 612-626-7600.

**Oct 25-28**  
The American Society for Bioethics and Humanities Annual Meeting in Nashville, TN. On 10/25 Jeffrey Kahn, PhD, MPH, and Susan M. Wolf, JD, will participate in a panel presentation “Preimplantation Genetic Diagnosis and the Ethics of Creating Donors.” Jeffrey Kahn, PhD, MPH, will also participate in a panel presentation “Bioethics as Policy: Experiences from Federal Advisory Committees.”

**Oct 28**  
On 10/27 Steven Miles, MD, will speak on “Bioethics and Activism.” For information, call 847-375-4745.

**Nov 1**  
Dianne Bartels, RN, MA, will participate in a community forum sponsored by the Minnesota Hospice Organization, “The Painful Truth,” featuring noted author and end of life advocate, Ira Byock, MD. The forum will be held at the St. Paul Technical College Auditorium from 7-9 pm. To register for this event, call 651-659-0423.

**Nov 2-4**  
On 11/2 Steven Miles, MD, will participate on a panel “Quality Health Care: Can We Identify It?” and on 11/4 will speak on “A New Interpretation of the Hippocratic Oath,” sponsored by the University of Chicago Law School and Medical School Conference. For information, call 773-702-1453.

**Nov 3**  
Jeffrey Kahn, PhD, MPH, will speak on “Ethical Challenges to Fulfilling the Promise of Stem Cells,” at the 2001 National Marrow Donor Program Council Meeting, Minneapolis, MN. For information, call 800-526-7809.

**Nov 6**  
Susan M. Wolf, JD, will lead a seminar at the National Institutes of Health (NIH) on the law regarding termination of life-sustaining treatment. For information, call 301-496-2429.

**Nov 8**  
Ted Marmor, PhD, Yale University, will speak at the Center for Bioethics seminar series on the University of Minnesota campus, 12:15-1:30 pm. For information, contact the Center.

**Nov 11**  
Jeffrey Kahn, PhD, MPH, will speak on “Ethical Issues in Stem Cell Research,” at MNBIO Annual Conference, Minneapolis, MN. For information, call 651-265-7840.

**Nov 29-Dec 1**  
Jeffrey Kahn, PhD, MPH, will speak on “Ethical Dilemmas in Cell-Based Therapy in Humans,” for the Islet Transplantation 2001 and Beyond from Research to Clinical Application conference, sponsored by the Annenberg Center for Health Sciences at Eisenhower, in Rancho Mirage, CA. For information, call 800-321-3690.

**Feb 14-15**  
Susan M. Wolf, JD, will serve as the Brin Visiting Professor in Medical Ethics at Johns Hopkins University School of Medicine and will deliver the Brin Lecture. For information, call 410-955-8842.

**Apr 3**  
Susan M. Wolf, JD, will lead a seminar at the National Institutes of Health (NIH) on the law regarding termination of life-sustaining treatment. For information, call 301-496-2429.
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The Winter 2002 Bioethics Examiner submission deadline is Wednesday, December 5. Submissions should be addressed to: Bioethics Examiner, Center for Bioethics, University of Minnesota, N504 Boynton, 410 Church Street SE, Minneapolis, MN 55455-0346. Telephone: 612-624-9440 Fax: 612-624-9108 E-mail: holmb006@tc.umn.edu

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