Should scientists use genetic engineering to make people “better than normal”? Should society allow people to sell their kidneys? Should human embryos be used for medical research? Should I participate in biomedical research? What questions should you ask before you consent to be a research participant? How can I make sure my healthcare wishes are followed if I am too sick to speak for myself? Should we use genetic engineering to change our cells and genes to extend our lives? How much is one year of life worth? Should brain implants be used in the future to increase intelligence? What would happen to individuality and identity if there were multiple genetic copies of people? Is the current distribution of healthcare resources fair and equitable? Is hospice care available to those Americans who need it? Are dying patients receiving adequate pain and symptom management? How effective are advance directives-documents that outline a patient’s choices for end of life care and are used when a patient can no longer communicate? Do Americans have a “right to die”? How far should we go to extend life? Do doctors, nurses and other health professionals have enough training to handle end of life decisions? Who should approach the family about donating their loved one’s organs after they die? Is there an ethical or moral difference between cloning to create a human being (reproductive cloning) and cloning to find cures for diseases (therapeutic cloning)? Would therapeutic cloning take away something fundamental about being human? Given the high rates of deformity, disability and death resulting from animal cloning, what are the likely risks to be encountered in human reproductive cloning? Can those risks be minimized? Are there potential social risks for cloned individuals? Will they be accepted as unique individuals? What would happen to individuality and identity if there were multiple genetic copies of people? Are “manufactured” and “made to order” humans in the best interest of society? Should those who have a better chance for survival be given priority over other patients needing organ transplants? Should parents of young children be given priority? Should those whose lifestyle choices (smoking, drinking, drug use, obesity, etc.) damaged their organ(s) be given a chance at an organ transplant? Should patients have a “right to die”? How far should we go to extend life? Should doctors, nurses and other health professionals have enough training to handle end of life decisions? Who should approach the family about donating their loved one’s organs after they die? Is there an ethical or moral difference between cloning to create a human being (reproductive cloning) and cloning to find cures for diseases (therapeutic cloning)? 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Should those who made the decision to donate organs of a loved one who has been declared dead receive any kind of financial compensation? Should everyone be required to indicate their wishes regarding organ transplantation on either their income tax forms or drivers license? Should consent to donate organs be presumed, so that organs are donated unless a person, while still living, specifically requests not to donate upon death? Should organs be created through the use of stem cells? Should hospital policies permit organs to be taken from non-heart-beating donors (NHBD) to increase the number of organs available? Are we encouraging pregnancy for profit with surrogacy options? What about other traits, including intelligence? What is the status of these embryos that are left over after a couple goes through the in vitro fertilization process? Are they “spare”? Do they have rights? Do people have a right to reproduce? If they do, can all means be used to assist conception? What about cloning? Embryo screening is causing a lot of pain? Is there a limit to how much pain is okay? Is an animal life worth the same as a human life? Could a financial incentive potentially influence research results? How should data from research involving human subjects be managed and safeguarded in order to protect privacy concerns? If healthcare resources are scarce, how should they be distributed? Distribution choices will benefit some and not others. How should choices be made? What values should guide these choices? Should Americans devote more resources to healthcare if they choose? Is the current distribution of healthcare resources fair and equitable? Is the current distribution of healthcare resources an efficient and wise use of funding? When does a human embryo become a person? Should we use research methods that destroy human embryos to search for new therapies that could help people in the future? How far are we as a society willing to go to improve our health and lives? Where should the embryos for stem cell research come from? Will stem cell research lead to future genetic manipulation of cells? Will we cease to be human if that happens? What are we willing to spend on medical research and who...
Our Mission

The mission of the Center is to advance and disseminate knowledge concerning ethical issues in biomedical research, health care and the life sciences. The Center carries out this mission by conducting original interdisciplinary research, offering educational programs and courses, fostering public discussion and debate through community outreach activities, and assisting in the formulation of public policy. The Center is open to all points of view regarding moral values and principles. Its research reflects a strong belief in combining the strengths of various disciplines and professions. When possible, research findings are integrated with policy analysis. The Center provides education in bioethics for University students, faculty, and staff, professionals in health care and related fields, and interested members of the general public.
From the Director

Those of us who work in bioethics are often asked difficult and challenging questions—it’s part of the job. This year at the Minnesota State Fair we had the chance to turn the tables. In the University building at the Fair, we tried something new at the Academic Health Center’s kiosk. We put up big signs that said “Can You Lick the Problem?,” with very large lollipops arrayed like bouquets of flowers on the tables where we sat.

In order to get one of the lollipops, visitors needed to write a short answer to one of three bioethics questions. The response was more than we predicted and better than we could have hoped. People have strongly-felt views about the ethical challenges we face as individuals and as a society (and a strong desire for free candy!), and we in the Center are gratified to be able to help the public better understand these issues through the range of things that we do. Throughout this report, you’ll see the questions and some of the answers we received from those who tried to “lick the problem,” along with a summary of overall responses.

Our work at the Fair was just part of our larger efforts, of course, and this was another successful year for the Center. Our faculty continue to do the work they are known for: engaged teaching, actively participating in the University community, and producing research and scholarship that gain them well-deserved national and international reputations. Even as we maintain our status as a premier bioethics program, it is important to reflect on where we have been and where we should be heading in the future. To that end, in 2004 the Center engaged in an internal and external review process, which helped us identify areas for future emphasis and growth, including additional endowments, and further development of our graduate program. Stay tuned for announcements in these and other areas as we begin to implement these new strategic initiatives.

As always, the Center’s efforts depend on funding and other support for our research and programs, from the University’s Academic Health Center, the Maas Family Foundation, the Starr Foundation, The Dorsey & Whitney Foundation, The Greenwall Foundation, the National Institutes of Health, and in programming and research partnerships like the University’s Consortium on Law and Values in Health, Environment & the Life Sciences.

As detailed in this report, the Center and its faculty continue our commitment to bioethics for a wide range of audience and through a variety of approaches, maintaining our status as a prominent and productive Center. We welcome your input on our efforts.

Sincerely,

Jeffrey Kahn, PhD, MPH
Director, and Maas Family Endowed Chair in Bioethics
Faculty News, Appointments and Awards

Dianne Bartels, RN, MA, PhD, was appointed as a member of the Minnesota Department of Health Newborn Screening Advisory Board; and member of Hospice of the Twin Cities Board of Directors.

Carl Elliott, MD, PhD, article on “Adventures in the Gene Pool” was named a “notable essay” in The Best American Essays 2004, edited by Louis Menand.

Jeffrey Kahn, PhD, MPH, was appointed member of the National Human Genome Research Institute, Social Behavioral & Economic Research Scientific Advisory Panel; member of the Task Force on Ethics Consultation Liability, American Association of Bioethics (ASBH); member-at-large, American Association for the Advancement of Science: Committee of the Section on Societal Impacts of Science and Engineering; Member, University of Minnesota Faculty Senate Committee on Committees; and guest editor with colleague, Anna Mastroianni for a special issue devoted to the future of bioethics in the Journal of Law, Medicine and Ethics.

Joan Liaschenko, RN, PhD, was elected Fellow to the American Academy of Nursing; and awarded the E. Louise Grant Award for Excellence in Nursing by the University of Minnesota School of Nursing.

Steven Miles, MD, was elected Fellow of the Hastings Center; appointed to the bioethics editorial board for the International Journal of Bioethics; and named 2004 Minnesotan of the Year by Minnesota Monthly.

Gregory Plotnikoff, MD, was awarded the 2004 Early Distinguished Career Award by the University of Minnesota Medical Alumni Society.

Edward Ratner, MD, was appointed Compliance Officer for the Community University Health Care Center, Minneapolis, MN; received a University of Minnesota Digital Media Center Fellowship; and voted as one of the top 100 Influential Leaders in Health Care in Minnesota by Minnesota Physician.

David Satin, MD, was appointed as a Postdoctoral Fellow in the Center for Bioethics in July 2004; awarded the Society of Teachers of Family Medicine Resident-Teacher Award; and the Minnesota Association of Family Practice Resident of the Year Award.

John Song, MD, MPH, MAT, was awarded a 2004 Gold Foundation Faculty Award by Minnesota Medical Foundation; awarded the 2004 Leonard Tow FacultyHumanism in Medicine Award by Minnesota Medical Foundation; Phillips Neighborhood Champion Award, Minneapolis, MN; and the 2004 Outstanding Community Service Award by the University of Minnesota Office of the Executive Vice President and Provost.

Carol Tauer, PhD, was appointed to the American College of Obstetricians and Gynecologists Committee on Ethics; the Ethics Advisory Board, Advanced Cell Technology, Worcester, MA; and the University of Minnesota Stem Cell Institute Ethics Advisory Board.

Maryam Valapour, MD, was appointed Graduate Faculty, Center for Bioethics, University of Minnesota; and appointed to the research committee for LifeSource Upper Midwest Organ Procurement Organization.

Susan Wolf, JD, was appointed Executive Editor for the Minnesota Journal of Law, Science and Technology.
Center Faculty

Dianne Bartels, RN, MA, PhD, is the Center's Associate Director and Adjunct Faculty Member in the School of Nursing and in Genetics, Cell Biology and Development at the University of Minnesota. Dr. Bartels has a Master's degree in Psychosocial Nursing from the University of Washington and a PhD in Family Social Science from the University of Minnesota. She co-teaches a course addressing ethical and legal issues in genetic counseling. Recent research and publications have focused on ethics and genetics in primary health care, psychosocial issues in genetic counseling, families and health technologies, as well as medical futility and other ethical issues in end of life care. Dr. Bartels has served on the Minnesota Commission on End of Life Care and was one of the founders of the first network of ethics committees in the state of Minnesota.

Debra DeBruin, PhD, is Assistant Professor and Director of Graduate Studies in the Center for Bioethics; and Assistant Professor, Department of Medicine, University of Minnesota Medical School. She received her PhD in philosophy from the University of Pittsburgh and was a Greenwall Postdoctoral Fellow in Bioethics and Health Policy at Johns Hopkins University. In addition to teaching philosophy and bioethics, Dr. DeBruin served as a health policy fellow for Senator Edward Kennedy (D-MA) in the Democratic Office of the Health, Education, Labor and Pensions Committee of the United States Senate. She has also worked as a consultant to the National Academy of Science's Institute of Medicine and the National Bioethics Advisory Commission on issues relating to the ethics of research. Her areas of interest include the ethics of research involving human subjects, and public health policy.

Carl Elliott, MD, PhD, is Associate Professor, Center for Bioethics; Department of Pediatrics, University of Minnesota Medical School; and Department of Philosophy, University of Minnesota. His most recent books include Better Than Well: American Medicine Meets the American Dream (Norton 2003) and Prozac as a Way of Life (UNC Press, 2004) co-edited with Tod Chambers. In 2003–4, he was Visiting Associate Professor in the School of Social Science at the Institute for Advanced Study in Princeton, NJ.

Jeffrey Kahn, PhD, MPH, is the Center's Director. He is also Maas Family Chair in Bioethics, and Professor in the Department of Medicine, University of Minnesota Medical School. He also holds appointments in the Division of Health Services Research and Policy, School of Public Health; and Department of Philosophy. Dr. Kahn holds a PhD in philosophy and bioethics from Georgetown University and a Master's of Public Health from the Johns Hopkins University School of Hygiene and Public Health. Dr. Kahn's current research areas include ethics in research on human subjects, ethics of stem cell research and related technologies, ethics and organ transplantation, and ethics and public health. He is the author of numerous books, journal articles and book chapters, serves on various advisory committees for the federal government and professional societies, and speaks around the country and internationally on a range of bioethics topics.

Joan Liaschenko, RN, PhD, is Associate Professor, Center for Bioethics; and School of Nursing, University of Minnesota. Dr. Liaschenko holds a PhD from the University of California, San Francisco where she also did postdoctoral work. She teaches ethics in the School of Nursing at the masters and doctoral level. Her research interests are in the moral dimensions of nursing work, feminist ethics, and humanities and nursing. Currently she is the Principal investigator on a National Institute of Nursing Research (NINR) funded study exploring the ethical concerns experienced by nurses working in biomedical clinical trials. Her Center colleague, Debra DeBruin, PhD, is a co-investigator. Dr. Liaschenko is the author of numerous journal articles and book chapters and is the co-editor of the journal, Nursing Philosophy. She also holds appointments as Adjunct Associate Professor of Nursing at the Universities of Toronto and Calgary, Canada, and has been a visiting scholar in Australia, Canada, and Japan.

Steven Miles, MD, is Professor in the Center for Bioethics and in the Department of Medicine, University of Minnesota Medical School. He received his MD from the University of Minnesota and did postgraduate work at United Theological Seminary. He is board-certified in Internal Medicine and Geriatrics and is a recipient of the Distinguished Service Award from the American Society for Bioethics and the Humanities. His research focuses on human rights, equitable access to health care, end of life care, and accidental deaths in restraints. His most recent book is The Hippocratic Oath and the Ethics of Medicine, published by Oxford University Press in 2004.
John Song, MD, MPH, MAT, is Assistant Professor in the Center for Bioethics; and in the Department of Medicine, University of Minnesota Medical School; and Staff Physician, Community-University Health Care Center (CUHCC). Dr. Song received his MD from the University of Pennsylvania and his MPH from the Johns Hopkins University School of Hygiene and Public Health. He trained in internal medicine at both the University of Minnesota and Johns Hopkins University and was a Greenwall Postdoctoral Fellow in Ethics and Public Policy at Johns Hopkins University. His areas of interest include the ethics of health care for homeless persons, HIV/AIDS care, end of life care and general medical ethics.

Maryam Valapour, MD, is Assistant Professor in the Center for Bioethics; and in the Department of Medicine, University of Minnesota Medical School. Dr. Valapour received her MD from the Medical University of South Carolina and completed her residency in internal medicine at Thomas Jefferson University. She subsequently completed fellowships in pulmonary and critical care medicine as well as bioethics and health policy at Johns Hopkins University. Dr. Valapour’s research interests include distributive justice as it relates to allocation of healthcare resources and to transplant ethics. In particular, she has focused on the fair distribution of organs. Her latest project examines the policies of transplant centers to allocate one versus two lungs in patients with chronic obstructive lung diseases, and whether that choice affects patient mortality.

Susan M. Wolf, JD, is Faegre & Benson Professor of Law and Professor of Law and Medicine, Law School and Center for Bioethics; Professor of Medicine, University of Minnesota Medical School; Director, Joint Degree Program in Law, Health & the Life Sciences; and Chair, Consortium on Law and Values in Health, Environment & the Life Sciences, University of Minnesota. She received her law degree from Yale Law School. Her areas of interest include law and medicine, law and science, genetics, reproductive technologies, managed care, health care reform, women’s health, termination of treatment, euthanasia, and the law and ethics that govern doctor-patient interactions. She is the editor of a book entitled Feminism and Bioethics: Beyond Reproduction (Oxford University Press, 1996) and has written numerous articles in legal, medical, and ethics journals.

Faculty Associates

Muriel Bebeau, PhD, is Professor in the Division of Health Ecology, Department of Preventive Sciences, University of Minnesota School of Dentistry. She is also Director of Education for the University’s Center for the Study of Ethical Development. She received her PhD in educational technology from Arizona State University. She has authored numerous articles on professional ethical development and its assessment. Her primary research interests are the processes involved in ethical decision-making (sensitivity, reasoning and judgment, commitment, and actions) and their role as determinants of ethical behavior. She is the author of numerous books, journal articles, and book chapters.

Ronald Cranford, MD, is Professor of Neurology, University of Minnesota Medical School; Senior Physician and Assistant Chief, Department of Neurology, Hennepin County Medical Center, Minneapolis, Minnesota. He received his MD from the University of Illinois College of Medicine, Chicago. His areas of interest include termination of treatment, brain death, persistent vegetative state, and institutional ethics committees. He was chairman of the first national meeting on institutional ethics committee and co-edited the first book on these committees, Institutional Ethics Committees and Health Care Decision Making (Health Administration Press, 1984). As a neurologist/clinical ethicist, he has been involved in ten landmark right to die cases in the courts, including Brophy in Massachusetts, Torres in Minnesota, Cruz in Missouri (to the US Supreme Court), Martin in Michigan, Wendland in California, and Schiavo in Florida.

Barbara Elliott, PhD, is Professor, Department of Family Medicine, University of Minnesota Medical School Duluth and serves as the Director of Clinical Research for the Department of Family Medicine; and has an appointment as Adjunct Professor in the Department of Behavioral Sciences. She received her PhD in medical and family sociology from the University of Minnesota, was a Visiting Scholar at the Hastings Center, and has held a Fellowship with the Kellogg National Leadership Program. Her research interests in bioethics focus on social justice issues in healthcare settings. She has developed programs to improve access to care for marginalized groups including parenting, at risk, and homeless teens, victims of family abuses, grieving families, and caregivers of the homebound. She chairs a hospital ethics committee and has created a community-based ethics project to develop community conversations around bioethics concerns.
Rosalie Kane, PhD, is Professor, Division of Health Services Research and Policy, School of Public Health; and Professor, School of Social Work, College of Human Ecology. She earned her MA degree from Simmons College School of Social Work and her PhD from the University of Utah. Her research interests in bioethics include conceptualizing and measuring a good quality of life for people receiving long-term care, exploring how to enhance autonomy for long-term care consumers in all settings including nursing homes, assisted living and their own homes; values assessment and preferences to long-term care professional decision making; and identifying ethical dilemmas in and standards for under-explored areas, such as case management, care coordination, and hospital discharge planning. Recently she has been exploring disparities in expenditures and care models for long-term care of elderly people compared to long-term care for younger people with disabilities. Her most recent books include Assessing Older Persons: Measures, Meaning, and Practical Applications (Oxford University Press, 2000); and The Heart of Long-Term Care (Oxford University Press, 1998).

David Mayo, PhD, is Professor of Philosophy, College of Liberal Arts, University of Minnesota, Duluth. He received his PhD in philosophy from the University of Pittsburgh. His current research interests include euthanasia, ethical issues surrounding suicide, and AIDS and privacy. His books include AIDS, Testing and Privacy (University of Utah Press, 1989), and Suicide: The Philosophical Issues (St. Martin's Press, 1981).

Gregory Plotnikoff, MD, MTS, is Associate Professor in the Departments of Internal Medicine and Pediatrics, University of Minnesota Medical School. He received his MD and residency training from the University of Minnesota. Prior to medical school, he received a Master of Theological Studies from Harvard University Divinity School where he also trained as a hospital chaplain. Dr. Plotnikoff specializes in cross-cultural and integrative medicine including the associated ethical issues in research, policy and practice. He is a contributing faculty member of the University's Center for Plants and Human Health, the Center for Dietary Supplement Safety and the Center for Spirituality and Healing. Dr. Plotnikoff currently divides his time between the University of Minnesota and Keio University Medical School in Tokyo, Japan.

Edward Ratner, MD, is Associate Professor, Department of Medicine, University of Minnesota Medical School. He received his MD from the University of Chicago, Pritzker School of Medicine. After his residency in Internal Medicine, he completed a fellowship in geriatrics at the University of Minnesota. Along with Drs. John Song and Dianne Bartels, Dr. Ratner is an investigator on an NIH funded project “End of Life Care for the Homeless.” Other funded research interests include telemedicine and handheld computer use in medicine. He is member of the Graduate School Faculty in Health Informatics. His clinical practice is focused on home care. In the Medical School, Dr. Ratner serves as Associate Course Director for the introduction to clinical medicine course, “Physician and Patient.” Dr. Ratner is a past president of the American Academy of Home Care Physicians and the president-elect of the Minnesota Medical Directors Association.

Karen-Sue Taussig, PhD, is Assistant Professor in the Department of Anthropology; and Assistant Professor, Department of Medicine, University of Minnesota Medical School. She received a PhD in social-cultural anthropology from Johns Hopkins University in 1997. She has held research grants from the National Science Foundation; the Wenner-Gren Foundation for Anthropological Research; and the Ethical, Legal, and Social Implications of Human Genetics Research, National Human Genome Research Institute, NIH. From 1997–99 she was a postdoctoral fellow in the Department of Social Medicine at Harvard Medical School. Her research in bioethics has focused on the emergence, circulation, and meaning of new genetic knowledge in the United States and Europe.

Beth Virnig, PhD, MPH, is Associate Professor in the Division of Health Services Research and Policy, School of Public Health, University of Minnesota. She received both her PhD and MPH in epidemiology from the University of Minnesota. Her current research in bioethics is on access to hospice use, such as whether elderly living in rural areas have limited access to hospice. She also studies racial and geographic variability in the quality of cancer care.
**Postdoctoral Fellow**

David Satin, MD, 2004–05 Postdoctoral Fellow, Center for Bioethics; Assistant Professor Department of Family Medicine and Community Health, University of Minnesota. Dr. Satin completed his Family Medicine residency training at the University of Minnesota, following a medical degree from the University of Western Ontario (Canada), a Robert Jones Scholarship in philosophy to the University of St. Andrews (Scotland), a philosophy degree from the University of Western Ontario and a health science degree from Marianopolis College in his home town of Montreal. He spends much of his time teaching medical students and residents while practicing at Smiley’s Clinic, a University family medicine clinic serving the local Minneapolis community and its homeless. Dr. Satin writes and speaks regularly about clinical applications of consent, societal considerations of genetic technologies, and how best to teach clinical ethics and professionalism to medical students and residents.

**Visiting Faculty**

Norman Berlinger, MD, PhD, Physician, Oakdale Ear Nose, and Throat, PA, Robbinsdale, MN. Dr. Berlinger’s research focused on the determination of whether trust in the physician correlates with better patient adherence to medical regimen and better patient outcomes. He recently finished writing a book about teen depression, Rescuing Your Teenager from Depression (HarperCollins, forthcoming 2005). He continues to write for the New York Times and various national magazines about medicine and science.

Raymond DeVries, PhD, Department of Sociology and Anthropology, St. Olaf College, is a sociologist with a long-standing interest in medicine and ethics. He is editor of Bioethics and Society: Constructing the Ethical Enterprise (Prentice Hall, 1998) and has published a number of articles on the profession of bioethics. He came to the Center as a recipient of a “Mentored Scientist Development Award in Research Ethics” from the NIH and is working with Jeffrey Kahn on an ethnographic study of decision-making in Institutional Review Boards. He is also a co-investigator on two other NIH-funded research projects: “Ethical and Policy Challenges Surrounding the Use of Deep Brain Stimulation (DBS) for Parkinson’s Disease,” and “Work Strain, Career Course, and Research Integrity.” His book, A Pleasing Birth: Midwifery and Maternity Care in the Netherlands, (Temple University Press) was published in early 2005; he is co-editor of, The View from Here: Social Science and Bioethics, to be published in 2006 (Blackwell).

Carol Tauer, PhD, is Professor Emerita of Philosophy, College of St. Catherine, St. Paul. She holds a PhD in mathematics from the Massachusetts Institute of Technology and a PhD in philosophy from Georgetown University. In 1994 she was appointed to the National Institutes of Health (NIH) Human Embryo Research Panel, which recommended ethical guidelines for federal funding of infertility and embryo research. In 1999 she served on a NIH panel that developed guidelines for funding embryonic stem cell research. Her research interests include human embryo and stem cell research, research involving children, end of life issues, genetic testing and screening, and maternal-fetal issues in pregnancy.

**Visiting Scholars**

The Center continues to host visiting scholars from around the world to work collaboratively with our faculty. In 2004, we had the privilege to host:

**Dr. Joy Bickley Ascher**, Senior Lecturer, Graduate School of Nursing and Midwifery, Victoria University of Wellington, Wellington, New Zealand. The focus of her work was on ethical issues in end of life care.

**Dr. Stephen Edwards**, Centre for Philosophy & Health Care, University of Wales, Swansea, United Kingdom. The focus of his work was on the relationship between disability and identity.

**Helen Kohlen, RN**, Doctoral Candidate, Political Science, University of Hanover, Germany. The focus of her work was on nursing ethics and ethics committees.
Research

The Center continues to conduct both conceptual and empirical research to provide scholars, policy makers and the public with the information and the understanding to confront ethical issues involved in biomedical research, health care, and technology. The following is an overview of our research efforts in 2004.

Newly Funded Research

Joan Liaschenko, RN, PhD, was awarded funding for a project on “An Investigation of Factors Influencing Critical Care Nurses’ Inclusion of Families in End of Life Care,” from the American Association of Critical Care Nurses (AACN).

John Song, MD, MPH, MAT, Edward Ratner, MD, and Dianne Bartels, RN, MA, PhD, were awarded a grant from the University of Minnesota Consortium on Law and Values in Health, Environment & the Life Sciences for their project on end of life planning for homeless persons.

Research Updates

Homelessness & End of Life Care

While focusing much energy and resources to providing good end of life (EOL) care and a “good death,” the American health care system has ignored those who die without loved ones by their sides, regular medical care, or safe and stable housing. EOL care for persons experiencing homelessness requires attention in our effort to transform the culture of dying in the United States. Drs. John Song, Edward Ratner, and Dianne Bartels are currently developing an NIH proposal to implement and evaluate interventions that homeless individuals, homeless service providers, and EOL experts believe necessary to improve the quality of EOL care for this population. The specific research question is: Can homeless individuals be educated and empowered to define, make decisions about, and effectively communicate their end of life care preferences?

An initial pilot study funded by the University of Minnesota’s Consortium on Law and Values found that EOL concerns are important to homeless persons, and that they welcome the opportunity to talk about these issues, as well as to demonstrate the feasibility of further investigation and to inform subsequent research design (accepted for publication, Journal of Clinical Ethics). With data from this study and input from an advisory group of homeless people and providers, we have recently completed an NIH-funded study utilizing focus groups of homeless individuals to explore participants’ conceptions of death, their hopes and fears, barriers to quality EOL care, and suggested interventions. This investigation found that some concerns are similar to those of previously studied populations, while other concerns are entirely unique and previously unreported — e.g. body disposal and anonymity in death (manuscript in preparation). A part of this study included questions inserted into the triennial survey of homelessness conducted by the Wilder Foundation (7,800 subjects) in order to explore the extent of these issues in the general homeless population; one finding is that over 40% of all respondents worried about EOL care at least several times per month (manuscript in preparation).

Nurses: Research Integrity in Clinical Trials

Joan Liaschenko, RN, PhD, and co-investigators Debra DeBruin, PhD, and Anastasia Fisher, RN, DNsc, University of San Diego, are proceeding with data analysis in their study of the ethical issues encountered by nurses working in clinical trials, and examining the implications of their findings for the responsible conduct of research. This research was supported by the Research on Research Integrity Program, an Office of Research Integrity/National Institutes of Health collaboration. It aims to develop an understanding of the ethical concerns encountered by clinical trial nurses, the institutional context in which those concerns are encountered, and the manner in which such concerns tend to be resolved. Although nurses bear responsibility for much of the day-to-day work of clinical trials, little is known about how they do their work or the ethical issues that they encounter in it. Data was collected in a series of focus groups with nurses working in clinical trials in Minnesota and California (manuscripts in preparation).
In addition, Liaschenko, DeBruin and Fisher have begun presenting their results in a number of venues, including the annual meeting of the Canadian Bioethics Society in October 2004, and the Office of Research Integrity’s Conference on Research Integrity in November 2004.

**Improving Disclosure and Decisions on Conflicts of Interest: An E-Curriculum**

Jeffrey Kahn was principal investigator working in collaboration with Peggy Sundermeyer (Office of the Vice President for Research) and Janet Shanedling (Academic Health Center Educational Resources) on this project, which involved two newly-created internet courses on conflict of interest.

The first course is geared towards researchers, providing them with information on decision making, managing conflicts of interest, and federal and state regulations. The second course will assist them in developing policies concerning the disclosure and the management of conflicts of interests. These courses consist of case studies, FAQs, definitions, and links to regulations.

**Promoting the Responsible Conduct of Clinical Research**

Debra DeBruin, PhD, is project director, and Jeffrey Kahn, PhD, MPH, is a member of a working group of prominent researchers from across the country that received a grant to investigate effective strategies for teaching the responsible conduct of clinical research. The study began with an online survey of members of the American Society of Bioethics and Humanities (ASBH) who teach the responsible conduct of clinical research. The online survey is being followed by more in-depth phone interviews with a number of these instructors. The working group intends to use information gleaned through the survey and interviews to identify the best practices for teaching this important topic. This research is funded by the U.S. Office of Research Integrity of the Department of Health and Human Services, and the Association of American Medical Colleges.

**Collaborative Research with University of Minnesota Departments and Other Academic Institutions**

- “Digital Scholarship and Practical Ethics” with the University of Virginia, Indiana University, and Duke University—funded by the Council on Library and Information Sciences.
- “Research Experiences for Undergraduates in the Biological Sciences” with the College of Biological Sciences, University of Minnesota—funded by the National Science Foundation.
- “International Bioethics Education and Career Development Award” with the Department of Sociology, St. Olaf College—funded by the Department of Health and Human Services (DHHS).
- “New Initiatives in Interdisciplinary Research and Post-Baccalaureate Education” with the Center for Excellence in Critical Care, University of Minnesota—funded by the Office of the Vice President for Research, University of Minnesota.
- “Consortium to Address Social, Economic, and Ethical Aspects of Biotechnology” with South Dakota State University—funded by the United States Department of Agriculture.
- “Gene(sis): Contemporary Art Explores Human Genomics” with the Frederick R. Weisman Museum at the University of Minnesota—funded by the Greenwall Foundation.
- “Project on Curriculum Development in Ethics and Public Health” with the Association of Schools of Public Health—funded by the Health Resources and Services Administration.
Publications

Books


Book Chapters


Special Journal Issues


Special issue of The Journal of Law, Medicine & Ethics, edited by Jeffrey Kahn and Anna Mastroianni

Articles


Elliott B, Gessert C, Peden-McAlpine C. When There’s No Quality of Life Left, It is Time to Die. *Quality of Life Research* 2004;13(2):457–462.


Reviews


Abstracts


Online Publications


Reports


Letters


Miscellaneous


Bioethics Examiner
In 2004, the Center for Bioethics published three volumes of the *Bioethics Examiner* with a circulation of more than 8,000 readers worldwide. Feature articles included:

“Patient Trust,” by Norman Berlinger, MD, PhD; Winter 2004 (Vol. 7. Issue 3).

“Pre-implantation Sex Selection in Japan,” by Gregory Plotnikoff, MD, MTS, FACP; Spring 2004 (Vol. 8. Issue 1).

“Genetic Counselors’ Impact on the Genetics Revolution: Recommendations of an Informed Outsider,” by Patricia McCarthy Veach, PhD, LP; Fall 2004 (Vol. 8. Issue 2).

Editorial Board Memberships and Peer Reviewers
Center faculty served as editors, advisors, editorial review board members, and peer reviewers for funders, professional journals, and academic presses including:

American Association of Dental Schools
American Educational Research Association
American Journal of Bioethics
American Journal of Managed Care
American Journal of Public Health
American Journal of Respiratory and Critical Care Medicine
*Annals of Internal Medicine*
Biosocieties
Brazilian Journal of Nursing
British Medical Journal
Canadian Medical Association Journal
Developing World Bioethics
Genetics in Medicine
Hastings Center Report
Health Affairs
Illness, Crisis and Loss
Journal of the American College of Dentists
Journal of the American Dental Association
Journal of the American Medical Association
Journal of Bioethics for the Developing World
Journal of Clinical Ethics
Journal of Dental Education
Journal of Dental Research

Journal of Ethics, Law, and Aging
Journal of Genetic Counseling
Journal of Health Politics, Policy and Law
Journal of Health Ethics (Online)
Journal of Law, Medicine and Ethics
Kennedy Institute of Ethics Journal
*Lancet*
MacArthur Foundation
Medical Care
Milbank Quarterly
National Academy of Sciences, Institute of Medicine (IOM)
National Endowment for the Humanities
National Human Genome Research Institute (NIH)
National Research Council
New England Journal of Medicine
New Zealand Journal of Bioethics
Nursing Philosophy
PERQ (Professions Education Research Quarterly) Advisory Board
Perspectives in Biology and Medicine
Science
Science and Engineering Ethics
Social Science and Medicine
Sociology of Health and Illness
Springer Verlag
Teaching and Learning in Medicine
Theoretical Medicine
Wellcome Trust Biomedical Ethics Programme, The United Kingdom
Education

The Center for Bioethics offers a broad range of courses and other educational programs and lectures to meet the needs of University faculty, students, staff, and professionals in health care and the social sciences. We provide leadership in University-wide efforts for training and educational programs in the responsible conduct of research. The Center also hosts student interns throughout the summer.

The following offers an overview of our educational efforts in 2004. For current course information, see our website at www.bioethics.umn.edu.

Philosophy 5325/8320
All students enrolled in the Graduate Minor in Bioethics are required to take a course in biomedical ethics, offered through the Department of Philosophy. Professor Carl Elliott currently teaches this course. It provides a graduate-level introduction to topics such as human subjects' research, informed consent, the withdrawal of life-sustaining treatment, euthanasia, enhancement technologies, and animal rights and welfare. Professor Elliott also regularly teaches an upper-level philosophy seminar on a topic related to medical ethics. Seminar topics include “Philosophy of Psychiatry,” “Cross-Cultural Bioethics,” “Bioethics and Fiction,” and “Enhancement Technologies and Human Identity.”

Nursing 8140
The University of Minnesota School of Nursing has a long history of ethics education at all three levels of the curriculum: baccalaureate, masters, and doctorate. Professor Joan Liaschenko teaches at both the masters and doctoral level. In her teaching, Dr. Liaschenko invites students to challenge traditional moral theory in health care in general and in nursing in particular. She encourages and challenges students to critique the moral understandings of health care in general and the particular clinical geographies in which they practice or conduct research.

Public Health 5741/5742 (courses also offered on-line)
Ethics in Public Health: Professional Practice and Policy and
Ethics in Public Health: Research and Policy
The University of Minnesota’s School of Public Health is one of the few public health schools in the US to require that all its graduate students complete education in public health ethics. Students must successfully complete a course in either research or professional practice ethics and are strongly encouraged to complete both. Professor Deb DeBruin directs the two courses that have been designed to meet this requirement.

The first course focuses on issues of public health practice and policy, and discusses topics such as the roles and values of public health professionals, health care rationing, environmental justice, and ethical issues in testing for disease, contact tracing, and compulsory treatment of disease. The second course concentrates on ethical issues in research, and examines basic policies governing research, with a special emphasis on moral issues such as informed consent, the inclusion of vulnerable populations in research, community research, and ethical standards for public health research in developing countries.

Genetic Counseling GCD 8913/8914
Ethical and Legal Issues in Genetic Counseling
This course is available to graduate students in genetic counseling and others interested in ethical and legal issues that are faced by health care practitioners who see clients with genetic concerns. Professors Dianne Bartels and Bonnie LeRoy co-facilitate this multidisciplinary course. Students learn how to review and assess relevant scientific and bioethics literature, and they engage in the process of individual and group decision-making about current ethical and legal challenges in human genetics.

Law School
Health Law 6875
This course examines the organization of health care delivery in the United States, how law structures health care delivery and constrains change, and alternative approaches to health care reform. Professor Susan Wolf teaches this Law School course, open to upperclass law students and others with instructor permission. Classroom time is devoted to analysis and debate of some of the most important legal and policy issues facing this country including quality-control regulation and malpractice reform, patients’ rights, patient privacy, health care finance and reform, and the division of regulatory responsibility between state and federal authorities.
Medical School

Physician and Society
The Center for Bioethics is responsible for providing ethics education for the University of Minnesota Medical School. Professor John Song serves as the Center’s Director for Medical Ethics Education. He directs ethics education for medical students, designing the curriculum, lecturing, recruiting guest lecturers and preceptors, and evaluating the students. He also directs ethics instruction for Internal Medicine residents, recruiting speakers and participating in morning reports, and teaches ethics in the core curriculum for all resident trainees.

Additional Programs
Dr. Song serves on several educational committees in the Medical School as the representative from the Center for Bioethics, ensuring that ethical concerns are incorporated into the broader curriculum. In the Department of Medicine, Dr. Song serves as the clinical preceptor to medical students and residents, and an evacuator for the Objective Structured Clinical Exams. Professor Jeffrey Kahn serves on the “On Doctoring” planning committee, which organizes four half-day sessions per year for third and fourth year medical students, on scientific, clinical, and social aspects of medicine.

MED 7598/7599
Professors Steven Miles and John Song provide independent study courses in ethics through the Department of Medicine.

Graduate Opportunities in Bioethics
The Center for Bioethics continues to attract high quality graduate and professional students to study bioethics at the University of Minnesota through a number of programs, including the Department of Philosophy, School of Public Health, Department of Medicine, School of Nursing, and the Law School, including the Joint Degree Program in Law, Health & the Life Sciences. The Center offers a range of opportunities for graduate study in bioethics, and in addition to coursework, sponsors regular activities including student luncheons, lectures, and an annual bioethics seminar series. Students planning an academic career in bioethics may be interested in writing a dissertation on a topic in bioethics. Dissertation advising by Center faculty is available. The Center also offers other graduate and professional students a variety of opportunities to tailor a program of study to their own special interests.

Graduate Minor in Bioethics
The Graduate Minor, administered by the Center for Bioethics, is designed for University of Minnesota graduate students interested in deepening their knowledge of the ethical issues surrounding health care and biomedical science. It is open to masters and doctoral students in any Graduate School department.

Joint Degree Program in Law, Health, & the Life Sciences
The Joint Degree Program (JDP) is designed for students interested in combining a law degree with one of the broad range of graduate degrees in health and the life sciences and often focuses their studies on bioethics. These students will become leaders in areas such as managed care and health policy, intellectual property issues in biotechnology, and environmental law and policy. Students in the program will be able to obtain a JD together with an MS or PhD in less time and with more academic support and potentially more financial support than if they pursued the two degrees separately.

Joint Degree Program Proseminar
The Joint Degree Program Proseminar is in many ways the intellectual and collegial hub of the Program. All students enrolled in the Joint Degree Program are required to register for the Proseminar. The Proseminar serves first to familiarize students in the Program with the wide range of interdisciplinary topics that they may wish to pursue in their scholarship and eventual careers. It is intended to showcase faculty affiliated with the program in order to acquaint students with the research being carried on by JDP faculty, and assist students in locating potential mentors and advisors. Finally, the seminar is intended to give students in the Program a class cohort.
MD/PhD Program

Through its Medical Scientist Training Program, the University of Minnesota is home to an MD/PhD program open to students who want to specialize in bioethics. Students can pursue a PhD in a discipline relevant to bioethics while also pursuing a medical degree.

University of Minnesota Courses Offered by Center Faculty & Associates include:

GCD 8913 Psychosocial Issues in Genetic Counseling
GCD 8914 Ethical and Legal Issues in Genetic Counseling
InMed 6051 Physician and Society
Law 6875 Seminar: Law, Health and Life Sciences
MED 7598 Biomedical Ethics
MED 7599 Bioethics Theory
NURS 8140 Moral and Ethical Positions in Nursing
Phil 5325 Biomedical Ethics
Phil 8320 Seminar in Medical Ethics: Wittgenstein and Ethics
PubH 5592 Reading in Clinical Research
PubH 5593 Directed Study: Clinical Research
PubH 5700 Foundations of Public Health
PubH 5708 Use of Administrative Data for Research
PubH 5741 Ethics in Public Health: Professional Practice and Policy
PubH 5742 Ethics in Public Health: Research and Policy
PubH 5784 Public Health Administration and Practice Masters Seminar
PubH 8803 Long-Term Care: Principles, Programs, and Policy

Lectures by Center faculty in University of Minnesota Programs included:

Biochemistry
Carlson School of Management
CHIP Student Committee on Bioethics Lecture Series
CLA Honors Seminar Book Discussion Panel
College of Biological Sciences
College of Continuing Education
Continuing Medical Education
Elder Learning Institute
Division of Epidemiology, School of Public Health
Genetics, Cell Biology & Development
Global Health Lecture and Seminar Series
Graduate Medicine Core Curriculum
Institute for Child Development
Joint Degree Program in Law, Health & the Life Sciences
School of Journalism
Medical School
“On Doctoring” Program
Family Practice & Community Health
Grand Rounds — Department of Medicine, Department of Pediatrics
Health Coalition for Non-Violence
Internal Medicine
Lung Transplant Medical Residents
Mini Medical School

John Song and Lucy Alderton
Outreach

The Center for Bioethics is a resource for health care professionals, students, policy makers, researchers and the public. The following activities in 2004 reflect our efforts in providing information to these audiences.

Resource Center

Supported by the Starr Foundation

In 2002, the Starr Foundation provided a three-year leadership grant to the Center for Bioethics to expand the availability of the Center's educational resources. This support has allowed the Center to develop and distribute educational materials to a broader audience of teachers, students, policy makers, and members of the general public.

The Resource Center acts as first responder, on behalf of the Center for Bioethics, to public requests for information. Online, the Resource Center hosts unique publications designed specifically for public access and responds to email inquiries that originate from visitors to our website.

In year three of the Starr Foundation grant, we were able to respond appropriately to resource requests from our primary audiences: health care professionals, college students (undergraduate and graduate), K–12 students and educators, university faculty and staff, and clergy. We redesigned our entire website so that it looks more visually inviting, is easier to use, and contains more resources on bioethics topics. (Please visit us online at www.bioethics.umn.edu/resources/.)

We published new resources to provide information on essential subjects in bioethics:

- **End of Life Care: An Ethical Overview** is now available online and in print from the Center for Bioethics Resource webpage. Topics include: defining death, research involving patients at the end of life, medical futility, palliative care, and ethical issues after death.

- **Law & Bioethics**, a new online feature, explains the interactions between the fields of law and bioethics and their combined impact on healthcare decisions that most people will face during their lifetimes. It includes examples of statutory and case laws.

- **Bioethics in the News**, also new online, places timely news stories within an ethical context. Our audience can learn about brain chips, ID implants, and online sales of organs for transplant.

We also added these new titles to our online Short Summary series: **Human Cloning, Organ Transplants and Resource Allocation**.

As part of our outreach efforts, the Resource Center maintains the listserv of the Minnesota Network of Healthcare Ethics Committees (MNHEC), keeping members informed of the Center for Bioethics lecture series and other public ethics education events.

Conferences

**Homelessness and End of Life Care Conference**

This invitational conference funded by the National Institutes of Health brought together University researchers, homeless service providers, end of life service providers, and people experiencing homelessness to discuss and identify the concerns of homeless people regarding death, dying and end of life care. The researchers (John Song, Dianne Bartels, and Edward Ratner) convened the meeting to share their research findings and to brainstorm about possible interventions that may provide comfort and dignity to those who are seriously ill or dying without the comfort of a home.
“A Call for a New Morality of Clinical Ethics” by Joan Liaschenko, RN, PhD, Associate Professor, Center for Bioethics; School of Nursing, University of Minnesota.

“Patient Trust” by Norman Berlinger, MD, PhD, Visiting Faculty, Center for Bioethics, University of Minnesota.

“The Advance Directive Not to Resuscitate: How Patients, Nurses, Doctors and Policy Advisors Compete for Control” by Joy Bickley Asher, PhD, Graduate School of Nursing and Midwifery, Senior Lecturer, Humanities and Social Sciences, Victoria University of Wellington, New Zealand.

“Disablement and Ideas of the Good Life” by Steven Edwards, PhD, Reader in Philosophy of Health Care, School of Health Science, University of Wales-Swansea, United Kingdom.

“Promoting Character Development of Our Nation’s Military Leaders: New Directions” by Muriel Bebeau, PhD, University of Minnesota Professor, Department of Preventive Sciences; Director, Center for the Study of Ethical Development; Adjunct Professor, Department of Educational Psychology; Faculty Associate, Center for Bioethics.

“Why Your Life is So Much Worse Than You Think” by David Benatar, PhD, Associate Professor, Department of Philosophy, University of Cape Town, South Africa.

“Global Health and a Frightened Empire” by Steven Miles, MD, Professor, Center for Bioethics; Department of Medicine, University of Minnesota Medical School.

WHAT THE PUBLIC THINKS — “CAN YOU LICK THE PROBLEM?”

Bioethics at the Minnesota State Fair—The Center distributed more than 500 lollipops to event participants that tried to “lick the problem” by answering one of three bioethics questions below.

1. Should scientists use genetic engineering to make people “better than normal” (taller, smarter, stronger, or live for a very long time) or only to treat genetic diseases?

There was a strong opinion that scientists should not use genetic engineering to make people “better than normal.” The majority felt we should only use the expertise to treat genetic diseases.

- 17% Yes
- 36% No
- 43% Only to treat genetic diseases
- 4% Undecided

2. Should society allow people to sell their kidneys when 17 people die every day because of a shortage of organs to transplant?

More than half of our visitors felt society should allow people to sell their kidneys, given that people are dying while waiting for organs for transplant.

- 52% Yes
- 47% No
- 1% Undecided

3. Should human embryos that are left over after assisted reproduction be used for medical research?

A strong majority of our visitors felt human embryos left over after assisted reproduction should be used for medical research.

- 77% Yes
- 21% No
- 2% Maybe
Co-sponsored Events

The Stem Cell Debate — Point-Counterpoint Discussion
Jeffrey Kahn, Catherine Verfaille, Stem Cell Institute Director, and Steve Calvin, Assistant Professor in Family Practice and Community Health, participated in a public forum on the science of embryonic stem cell research and the controversies around conducting it. This event was sponsored the Academic Health Center, University of Minnesota.

Science on Screen
“Gattaca” featured speaker Jeffrey Kahn in a post-film discussion. This event was sponsored by the University of Minnesota Bell Museum and Minnesota Film Arts.

Gene(sis): Contemporary Art Explores Human Genomics
Human Genomics Town Hall Meetings, cosponsored with the Weisman Art Museum and Design Institute, University of Minnesota.

Co-sponsored Conferences

Deinard Memorial Lecture on Law & Medicine
“The Crisis in Patient Safety and Malpractice: Fixing Medicine and Law” by Professor Troyen A. Brennan, MD, JD, MPH, Harvard University. Co-Sponsored with the Joint Degree Program in Law, Health & the Life Sciences.

Consortium on Law, and Values, in Health, Environment & the Life Sciences
The Consortium links the Center for Bioethics and sixteen other leading Centers and programs at the University of Minnesota to address the legal, ethical, and policy implications of the life sciences.

President’s 21st Century Interdisciplinary Conference Series

“Environmental Threats to Children’s Health: Legal and Policy Challenges.” Speakers included John Routt Reigart, MD; Wendy Wagner, JD; Rabbi Danie Swartz; Peter Nathanielsz, MD, PhD, ScD; and Robert Bullard, PhD.

“Intellectual Property Rights for the Public Good: Obligations of U.S. Universities to Developing Countries.” Speakers included Ronald Phillips, PhD; Susan Wolf, JD; Philip Pardey, PhD; Robert Goodman, PhD; Michael Taylor, JD; Susan Sell, PhD; Anatole Krattinger, MPhil, PhD; Mark Janis, JD; David Hamilton, PhD; Charles Muscoplat, PhD; James Chen, JD; Ruth Okediji, LLM, SJ; and Dan Burk, JSM, JD, MS.

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

“Financial Conflicts of Interest in Biomedical Research” by David Korn, MD, Association of American Medical Colleges, with commentators Norman Bowie, PhD and David Hamilton, PhD.

“Stem Cell Biology: Good Ethics Depend on Good Facts” by Evan Snyder, MD, PhD with commentators Paul Tuite, MD, and Jeffrey Kahn, PhD, MPH.

Lunch Series on the Societal Implications of the Life Sciences

“Ecology, Ethics, and Private Land” by Eric Freyfogle, JD.

“The Ironic Politics of Obesity” by Marion Nestle, PhD, MPH.

“Risk, Reason & Regulation of Medical Devices” by Michael Lysaght, PhD.

Should human embryos that are left over after assisted reproduction be used for medical research?

“I think left over human embryos should be used for research because what else would they do with them but destroy them. Why not find a cure for Alzheimer’s or Parkinson’s?”
Faculty Service on University of Minnesota
Committees & Boards

AHC Comprehensive Review Committee
AHC Faculty Advisory Committee, Center for Health Interdisciplinary Programs
Admissions Committee, Medical School
Advisory Committee for Research and Grants Management Education
Analytic Concentration Committee, School of Public Health
Biomedical Library Director Search Committee
Blood-Borne Disease Policy Committee, Medical School
Center for Bioethics Self Study Evaluation Task Force
Center for Global Health Executive Committee
Center for Holocaust and Genocide Studies Advisory Board
Clinical Medicine I, Medical School
Clinical Research Panel, Graduate School
Consortium on Law and Values in Health, Environment & the Life Sciences, Executive Committee
Faculty Advisory Committee, Public Health Certificate in Core Concepts
Faculty Education Advisory Committee on Responsible Conduct of Research
Faculty Senate Committee on Committees
Fairview University Medical Center, Ethics Committee
Genetic Counseling Graduate Program Admissions Committee
Joint Degree Program in Law, Health, and the Life Sciences Governing Committee
Mark and Judi Yudof Fellowship Award Committee
Medical Education Research Council, Medical School
Minnesota Partnership for Biotechnology and Medical Genomics Ethics Committee
On-Doctoring Program Steering Committee, Medical School
Physician and Patient Steering Committee, Medical School
Physician and Society Steering Committee, Medical School
Physician Well-Being Committee, Medical School
Primary Care Clerkship Steering Committee, Medical School
Research and Grants Management Education
Steering Committee, Medical School
Stem Cell Ethics Advisory Board
Veterinary Public Health Admissions Committee

Faculty Service on State, National and International Boards and Committees

Advanced Cell Technology Ethics Advisory Board
American Association for Dental Research Board
American College of Obstetricians and Gynecologists, Committee on Ethics
American Medical Association-Health Resources and Services Administration (HRSA) Advisory Committee on Organ Donation
American Public Health Association Governing Council; Liaison Board, HuGE (Human Genome Epidemiology)
American Refugee Committee
American Society for Bioethics and Humanities Task Force on Ethics Consultation Liability
Data Safety and Monitoring Board, The Environmental Determinants of Diabetes in the Young Study (TEDDY), National Heart, Lung and Blood Institute (NHLBI), National Institutes of Health (NIH)
Department of Health and Human Services/HRSA Division of Transplantation External Advisory Committee
International Myeloma Foundation Bank on a Cure Advisory Board
International Philosophy of Nursing Society Executive Committee
LifeSource (OPO) Medical Ethics Advisory Committee
Minnesota Asian American Health Coalition
Minnesota Department of Health Data Review Committee for the Minnesota Cancer Plan; and Newborn Screening Advisory Board
Minnesota Volunteers of America Board Member
National Children's Study Ethics Working Group
National Human Genome Research Institute (NHGRI) Social, Behavioral, and Economic Research (SBER) Scientific Advisory Panel
National Institutes of Health (NIH) Review Panel for Sociology, Nursing, Epidemiology and Methods
Oversight Committee for the Geographic Information System (GIS) for the Long Island Breast Cancer Study Project (LIBCSP), National Cancer Institute
Robert Wood Johnson Foundation Grant Review Committee
Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT), Data and Safety Monitoring Board (DSMB), National Institutes of Health (NIH)
United Network of Organ Sharing (UNOS) Ethics Committee
Upper Midwest Organ Procurement Organization Research Committee
Urban Coalition Health Advisory Board
Center faculty presented their work and delivered lectures in a variety of public settings

**Local and Regional Presentations**

- 5th Annual “Cutting Edge: New Frontiers in Transplantation” Conference  
  University of Minnesota, Minneapolis, MN
- 7th Annual Florence Schorske Wald Lectureship  
  University of Minnesota School of Nursing  
  Minneapolis, MN
- Abbott Northwestern Hospital Grand Rounds  
  Minneapolis, MN
- Albert Lea Medical Center Lecture  
  Albert Lea, MN
- Allina’s International Health Care Forum  
  Minneapolis, MN
- American Medical Students Association — University of Minnesota Chapter  
  Minneapolis, MN
- Augsburg College Physicians Assistant Program  
  Minneapolis, MN
- Baha’i Center  
  Minneapolis, MN
- Bethel University New Brighton, MN
- Carleton College Issues in Christian Ethics  
  Northfield, MN
- Century College Honors Council White Bear Lake, MN
- College of St. Catherine  
  St. Paul, MN
- Great Conversations University of Minnesota  
  Minneapolis, MN
- Inver Hills Community College Inver Grove Heights, MN
- Karolinska Institute Symposium  
  Minneapolis, MN
- Lake Fellowship of Unitarian-Universalists Shoreview, MN
- Luther Seminary  
  Minneapolis, MN
- Mayo Clinic Schools of Nursing and Medicine Rochester MN
- Medical Alley  
  Minneapolis, MN
- Mercy/Unity General Medical Staff Meeting  
  Fridley, MN
- Minnesota American Association of University Women (AAUW)  
  Minneapolis, MN
- Minnesota Academy of Family Physicians  
  Minneapolis, MN
- Minnesota Academy of Family Practice Annual Meeting  
  St. Louis Park, MN
- Minnesota Association of Black Physicians Annual Meeting  
  Minneapolis, MN
- Minnesota Colorectal Cancer Consortium Summit  
  St. Paul, MN
- Minnesota Medical Directors Annual Meeting  
  Minneapolis, MN
- Minnesota Medical Foundation Heritage Society  
  Minneapolis, MN
- Minnesota Nursing Home Association  
  St. Paul, MN
- Minnesota Public Health Association Chaska, MN
- Minnesota State University, Mankato  
  Mankato, MN
- National Infertility Association (RESOLVE) Minnesota Chapter Meeting  
  Brooklyn Park, MN
- Oak Grove Presbyterian Church Bloomington, MN
- Plymouth Congregational Church Minneapolis, MN
- Randolph High School Tour of Stem Cell Institute  
  Minneapolis, MN
- Retired Educators of Minnesota Minneapolis, MN
- Minnesota Health & Housing Alliance Roundtable  
  Minneapolis, MN
- St. Joseph’s Hospital Noon Conference  
  St. Paul, MN
- St. Michael’s Lutheran Church Roseville, MN
- St. Patrick’s Catholic Church Hudson, WI
- Smiley’s Clinic Practice Management Lecture Series  
  Minneapolis, MN
- Temple Israel Minneapolis, MN
- United Theological Seminary Series Minneapolis, MN

Former University Regent Maureen Reed, Steven Miles, and Mary Tate at a reception in honor of Steven Miles being named “2004 Minnesotan of the Year” by *Minnesota Monthly*
National & International Presentations

1st National Nursing and Ethics Symposium
Abant Izzet Baysal University
Bolu, TURKEY

2nd Annual African Genome Conference
Ain Shams University
Cairo, EGYPT

2nd International Conference on Abdominal Organ Transplantation from Living Donors
Taormina, Sicily, ITALY

4th International Symposium on Brain Death and Coma
International Association of Neurology
Havana, CUBA

8th International Philosophy of Nursing Conference
Centre for Philosophy, Humanities and Law in Healthcare
University of Wales, Swansea
Wales, UNITED KINGDOM

10th Annual Kansas Health Ethics Conference
Wichita, KS

10th Annual Conference on Teaching Survival Skills and Ethics
Snowmass, CO

11th Annual Conference of the International Society for Quality of Life Research
Hong Kong, CHINA

2004 National Conference on Health Care and Domestic Violence
Washington, DC

Ackerman Symposium on Professional Values in and Age of Consumer Medicine
Harvard University
Cambridge, MA

Advocate Health Care Conference on Achieving Excellence in Clinical Research
Oakbrook, IL

Alliance of McLaughlin Research Institute and Benefits Healthcare
Great Falls, MT

American Academy of Neurology 56th Annual Meeting
San Francisco, CA

American Medical Directors Annual Meeting
Phoenix, AZ

American Philosophical Association, Pacific Division Annual Meeting
Pasadena, CA

American Public Health Association 132nd Annual Meeting
Washington, DC

American Society for Bioethics and Humanities Annual Meeting
Philadelphia, PA

American Society for Nutritional Sciences
Washington, DC

American Educational Research Association Meeting on Defining Research Integrity and Conceptual Frameworks for Assessment
San Diego, CA

Annenberg Center for Health Sciences, Medical Grand Rounds
Palm Springs, CA

Bioethique 2004
Montreal, CANADA

BioPharmaceutical Technology Center Annual Conference
Madison, WI

California State Polytechnic University Pomona Annual Ethics Conference
Pomona, CA

Canadian Bioethics Society 16th Annual Meeting
Calgary, Alberta, CANADA

Carolinas Medical Center
Charlotte, NC

China Medical Board Project on Ethics of Research
Hangzhou, CHINA and Chengdu, CHINA

Davidson College
Davidson, NC

DePaul University College of Law
Chicago, IL

Duke University Divinity School
Durham, NC

Federation of American Societies for Experimental Biology Annual Meeting
Washington, DC

International Association of Bioethics 7th World Congress
Sydney, AUSTRALIA

Kaiser Hospital Pharmaceutical Ethics Conference
Sacramento, CA

Kidney & Urology Foundation of America
Annual Conference
New York, NY

Memorial Sloan-Kettering Cancer Center Pediatric Grand Rounds
New York, NY

Mount Sinai School of Medicine
New York, NY

National Conference on Health Care and Domestic Violence
Washington, DC

National Health Care for the Homeless
New Orleans, LA

National Organization of Rare Disorders Conference
Bloomington, MN

Northwestern University Low Tech Medicine Seminar
Chicago, IL

Office of Research Integrity Annual Research Meeting
San Diego, CA

Robert Wood Johnson Medical School Department of Psychiatry Grand Rounds
Camden, NJ

Robert Wood Johnson Symposium on Medical Enhancement and Health Economics
University of Chicago
Chicago, IL

Samuel Tishman Lecture
University of Pittsburgh School of Medicine
Pittsburgh, PA

Serono Symposium on ART and Embryo Law
Cambridge, MA

Seoul National University/University of Minnesota 50th Anniversary Celebration
Minneapolis, MN

Society for Neuroscience Priorities for 21st Century Neuroethics
San Diego, CA

Society of Teachers of Family Medicine 37th Annual Spring Conference
Toronto, CANADA

Third Annual International Bioethics Forum
University of Wisconsin
Madison, WI

United Resource Networks 5th Annual Emerging Technologies and Innovative Approaches Conference
New Orleans, LA

University of California, Davis Medical Grand Rounds
Davis, CA
Should society allow people to sell their kidneys when 17 people die every day because of a shortage of organs to transplant?

“I don’t believe people should ‘sell’ their organs – rather they should be encouraged to and educated about organ donation.”
Media Appearances

Print Media
AHC Pictures of Health
American Medical News
Associated Press
The Australian
Birmingham Evening Mail (UK)
Bloomberg News
Boston Globe
Charlotte Observer
Chicago Tribune
Child Magazine
Christian Science Monitor
Denver Post
Esquire
Gazette (Montreal)
Gotham Gazette
Guardian (London)
Guardian Weekly
Guelph Mercury (Ontario)
Halifax Daily News (Nova Scotia)
Hamilton Spectator (Ontario)
Hartford Courant
Hastings Star Gazette
Houston Chronicle
Irish Times
Johannes Wier Stichting
Journal of American Bar Association
London Review of Books
Los Angeles Times
Medical Bulletin, University of Minnesota Medical School
Medical Sociology News
The Mercury (Australia)
Milwaukee Sentinel
Minneapolis Star Tribune
Minnesota Daily
Minnesota Health Care News
Minnesota Magazine, University of Minnesota Alumni Association
Minnesota Medicine
Minnesota Monthly
Minnesota Physician
Money Magazine
The Morning Star (UK)
The National Post (Canada)
Nations Health
New York Times
The Ottawa Citizen (Canada)
Philadelphia Inquirer
The Record (Ottawa, Canada)
Regional Daily (London)
Science Magazine
St. Paul Pioneer Press
Seattle Press Intelligencer
The Standard (Canada)
Times Columnist (Canada)
Townsville Bulletin (Australia)
United Press International
US News & World Report
USA Today
Update, University of Delaware Student Newspaper
Vancouver Sun (Canada)
Ventura County Star
Wall Street Journal
Washington Post
The Weekend Australian
Windsor Star (Canada)

Online Media
AHC News Capsules
Arab Media Watch
HealthDay
IndyMedia Victoria
Twin Cities.com
University of Minnesota News Service
Web MD

Radio and Television
AirAmerica
Arnie Arneson Radio Show, New Hampshire
CBS Morning News
CNN
CTV (Canada)
KARE 11 News
Minnesota Public Radio
Neil Rogers Show
National Public Radio — All Things Considered; Lance Orosco Show; Ross Reynolds Show; Science Friday
PBS NewsHour
Radio City
Seattle Public Radio
UPN 29 News
Voice of America (China) Radio
WCCO Radio

Should human embryos that are left over after assisted reproduction be used for medical research?

“If they’re real kids, who takes responsibility after the research?”
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Should scientists use genetic engineering to make people “better than normal” (taller, smarter, stronger, or live for a very long time) or only to treat genetic diseases?

“Who says taller, smarter, stronger, etc. is better?”
Our Mission

The mission of the Center is to advance and disseminate knowledge concerning ethical issues in biomedical research, health care and the life sciences. The Center carries out this mission by conducting original interdisciplinary research, offering educational programs and courses, fostering public discussion and debate through community outreach activities, and assisting in the formulation of public policy. The Center is open to all points of view regarding moral values and principles. Its research reflects a strong belief in combining the strengths of various disciplines and professions. When possible, research findings are integrated with policy analysis. The Center provides education in bioethics for University students, faculty, and staff; professionals in health care and related fields; and interested members of the general public.
Should scientists use genetic engineering to make people “better than normal”? Should society allow people to sell their kidneys? Should human embryos be used for medical research? Should I participate in biomedical research? What questions should you ask before you consent to be a research participant? How can I make sure my healthcare wishes are followed if I am too sick to speak for myself? Should we use genetic engineering to change our cells and genes to extend our lives? How much is one year of life worth? Should brain implants be used in the future to increase intelligence? What would happen to individuality and identity if there were multiple genetic copies of people? Is the current distribution of healthcare resources fair and equitable? Is hospice care available to those Americans who need it? Are dying patients receiving adequate pain and symptom management? How effective are advance directives—documents that outline a patient’s choices for end of life care and are used when a patient can no longer communicate? Do Americans have a “right to die”? How far should we go to extend life? Do doctors, nurses and other health professionals have enough training to handle end of life decisions? Who should approach the family about donating their loved one’s organs after they die? Is there an ethical or moral difference between cloning to create a human being (reproductive cloning) and cloning to find cures for diseases (therapeutic cloning)? Would reproductive cloning take away something fundamental about being human? Given the high rates of deformity, disability and death resulting from animal cloning, what are the likely risks to be encountered in human reproductive cloning? Can those risks be minimized? Are there potential social risks for cloned individuals? Will they be accepted as unique individuals? What would happen to individuality and identity if there were multiple genetic copies of people? Are “manufactured” and “made to order” humans in the best interest of society? Should those who have a better chance for survival be given priority over other patients needing organ transplant? Should parents of young children be given priority? Should those whose lifestyle choices (smoking, drinking, drug use, obesity, etc.) damaged their organ(s) be given a chance at an organ transplant? Should incentives, either monetary or non-monetary, be offered in order to encourage organ donation? Should those who made the decision to donate organs of a loved one who has been declared dead receive any kind of financial compensation? Should everyone be required to indicate their wishes regarding organ transplantation on either their income tax forms or drivers license? Should consent to donate organs be presumed, so that organs are donated unless a person, while still living, specifically requests not to donate upon death? Should organs be created through the use of stem cells? Should hospital policies permit organs to be taken from non-heart-beating donors (NHBD) to increase the number of organs available? Are we encouraging pregnancy for profit with surrogacy options? What about other traits, including intelligence? Is causing an animal pain ever justified? Would it ever be okay to inflict a lot of pain? Is there a limit to how much pain is okay? Is an animal life worth the same as a human life? Could a financial incentive potentially influence research results? How should data from research involving human subjects be managed and safeguarded in order to protect privacy concerns? If healthcare resources are scarce, how should they be distributed? Distribution choices will benefit some and not others. How should choices be made? What values should guide these choices? Could Americans devote more resources to healthcare if they chose? Is the current distribution of healthcare resources fair and equitable? Is the current distribution of healthcare resources an efficient and wise use of funding? When does a human embryo become a person? Should we use research methods that destroy human embryos to search for new therapies that could help people in the future? How far are we as a society willing to go to improve our health and lives? Where should the embryos for stem cell research come from? Will stem cell research lead to future genetic manipulation of cells? Will we cease to be human if that happens? What are we willing to spend on medical research and who...