From the Director

This was another successful and productive year in the Center for Bioethics. Our faculty continue to be active teachers, researchers, and participants in the University community, and we continue to make a difference, locally, nationally, and internationally. A number of examples from this year come to mind:

- The health care clinic for the homeless started by John Song continues to offer free care to those who need it most, staffed by Academic Health Center professional students and faculty;
- the University's Stem Cell Ethics Advisory Board has three members, including its chair, from among Center faculty;
- the University's Consortium on Law and Values in Health, Environment & the Life Sciences, chaired by Susan Wolf, continues to host innovative programs and impressive speakers, drawing audiences from both inside the University and from across the region;
- Steve Miles continues to present and publish on novel issues relevant both at home and abroad, including during invited visits to Cuba, Iran, Turkey and Egypt; and
- Joan Liaschenko brought her unique insights as a visiting professor in Canada, Japan and the United Kingdom.

The Center's efforts continue to focus on the goals of our research, education, and outreach missions. We have maintained our status as one of the nation's premier bioethics programs, as part of the overall University goal to continue as a leading research university.

As always, our success depends in large part on those who support our efforts. In 2003 we were very fortunate to complete an endowed chair campaign and were thrilled to announce the formation of the Maas Family Chair in Bioethics, thanks to the generous contributions of the Maas Family Foundation, Fairview-University Medical Center, The Hubbard Foundation, and numerous others, along with generous matching funds from the President’s University Fund of the University of Minnesota. I am honored to be the first occupant of the new endowed chair.

Finally, the Center's efforts depend on funding for our research and programs, and it is important to mention them by name: 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, 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 offering expertise in bioethics to a wide range of audiences and through a variety of approaches, maintaining our status as a prominent and productive Center. We welcome your input and thoughts on our efforts.

Sincerely,

Jeffrey Kahn, PhD, MPH
Director, Center for Bioethics

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 program 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.

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2003 Annual Report Center for Bioethics
Dianne Bartels, PhD, RN, MA, was appointed to the University of Minnesota Senate Research Committee.

Muriel Bebeau, PhD, was awarded the Meritorious Civilian Service Award by the US Department of the Army.

Debra DeBruin, PhD, was appointed as Director of Graduate Studies at the Center for Bioethics, University of Minnesota.

Raymond deVries, PhD, was invited as a Visiting Scholar for the 2003-04 academic year at the School of Social Science, Institute for Advanced Study, Princeton, NJ.

Carl Elliott, MD, PhD, was named one of the top 10 local authors by Mpls.St.Paul Magazine; elected as a Fellow of the Hastings Center; and awarded a Visiting Professorship at the School of Social Science, Institute for Advanced Study, Princeton, NJ for one year beginning July 2003.

Jeffrey Kahn, PhD, MPH, was named the first holder of the endowed Maas Family Chair in Bioethics; elected as Fellow of the Hastings Center; appointed Chair of the University of Minnesota Stem Cell Advisory Board; appointed Chair, Ethics Working Group, Minnesota Partnership for Biotechnology and Medical Genomics, University of Minnesota/Mayo Clinic; appointed as Member, Data Safety and Monitoring Board, The Environmental Determinants of Diabetes in the Young Study (TEDDY), NHLBI, National Institutes of Health (NIH); and appointed Chair, NHGRI Special Emphasis Panel: Ethical, Legal, and Social Implications of Genetics, NIH.

Jonathan Kahn, JD, PhD, was appointed as Editor of the Bioethics Examiner, at the Center for Bioethics, University of Minnesota.

Rosalie Kane, PhD, and Robert Kane, PhD, were honored with the 2003 Dutch Kastenbaum Outstanding Gerontologist Award. The honor is given annually to those who make a significant contribution to the lives of older people in Minnesota, through research, practice, or academics.

Bonnie LeRoy, MS, CGC, Center Associate, received the Natalie Weisberger Award from the National Society of Genetic Counselors. The award is given annually to a genetic counselor who demonstrates exceptional lifetime leadership qualities in the profession of genetic counseling.

Joan Liaschenko, RN, PhD, was appointed as Visiting Scholar, Department of Nursing, College of Medical Technology, Hokkaido University, Sapporo, Japan.

Steven Miles, MD, was appointed to the National Consensus Project on Quality Palliative Care Advisory Committee; appointed to the National Advisory Board, Center to Advance Palliative Care, Mount Sinai School of Medicine for the Robert Wood Johnson Foundation; and appointed Chair, Human Subjects Review Committee, Center for Victims of Torture, Minneapolis.

Edward Ratner, MD, was promoted to Associate Professor, Department of Internal Medicine, University of Minnesota; awarded the Herz Faculty Development Award by the University of Minnesota; elected as President-elect of the Minnesota Medical Directors Association; and appointed attending physician at the Community University Health Care Clinic (CUHCC).

John Song, MD, MPH, MAT, was named lead investigator of the University of Minnesota Medical School’s participation in the American Medical Association's (AMA) Strategies for Teaching and Evaluating Professionalism (STEP) program. The University of Minnesota is one of 10 partner schools chosen by the AMA to participate.

Carol Tauer, PhD, was appointed to the Faculty Workgroup on “Disabling Disparities: Variations in the Treatment of Children, Adults, and Older Adults with Disabilities” for the Center on Aging, University of Minnesota; appointed to the Committee on Ethics, American College of Obstetricians and Gynecologists; and appointed to the Ethics Advisory Board, Advanced Cell Technology, Worcester, MA.

Karen-Sue Taussig, PhD, was appointed to the Graduate Faculty, Minor in Human Genetics, University of Minnesota.

Susan Wolf, JD, was appointed as Member, Ethics Working Group, Minnesota Partnership for Biotechnology and Medical Genomics, University of Minnesota/Mayo Clinic.
Center Faculty

Dianne Bartels, RN, MA, PhD, is the Center’s Associate Director and Adjunct Faculty Member in the School of Nursing, 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, and ethical issues in end of life care.

Debra DeBruin, PhD, is Assistant Professor and Interim 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 in the Center for Bioethics and Director of Graduate Studies for the Graduate Minor in Bioethics. He is also Associate Professor in the Department of Pediatrics, University of Minnesota Medical School; and Department of Philosophy, University of Minnesota. His most recent book is Better Than Well: American Medicine Meets the American Dream (Norton 2003.) He is also co-editor with Tod Chambers of the forthcoming collection, Prozac as a Way of Life (UNC Press). 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, and speaks around the country and internationally on a range of bioethics topics.

Jonathan Kahn, JD, PhD, is Research Scholar in the Center for Bioethics; Senior Research Fellow, Consortium on Law and Values in Health, Environment & the Life Sciences and the Joint Degree Program in Law, Health & the Life Sciences, Law School; and Lecturer, Department of Political Science, College of Liberal Arts, University of Minnesota. Dr. Kahn holds a PhD in History from Cornell University and a JD from Boalt Hall School of Law, University of California. He came to the University of Minnesota from Harvard University where, from 1999 to 2001, he was a Visiting Associate Professor of Social Studies. He is currently principal investigator on a National Institutes of Health (NIH) grant titled, “Colliding Categories: Haplotypes, Race and Ethnicity.” Dr. Kahn writes on a wide range of issues in history, politics, and law, with a special focus on the implications of biotechnology for our ideas of identity and citizenship. His recent work explores the legal and ethical implication of how racial categories are produced and disseminated in the course of drug development. His publications include a book, Budgeting Democracy: State-Building and Citizenship in America, 1890-1928 (Cornell University Press, 1997), and numerous journal articles.

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 Professor, 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 a recipient of the Distinguished Service Award from the American Society for Bioethics and the Humanities. The focus of his research is on end of life care, equitable access to health care, international health 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 2003.

John Song, MD, MPH, MAT, is Assistant Professor in the Center for Bioethics; Assistant Professor, 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 Assistant Professor, 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 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; 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; Chair, Consortium on Law and Values in Health, Environment & the Life Sciences; and Faculty Member, Center for Advanced Feminist Studies, University of Minnesota. She received her law degree from Yale Law School. Her areas of interest include law and medicine, end of life issues, genetics, reproductive technologies, managed care, health care reform, women’s health, termination of treatment, euthanasia, HIV and AIDS, medical futility, ethics committees, 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.

“We have never in human history faced this kind of demographic transition of having 20 percent of the population in a category called elderly. It just hasn’t happened.”

*Steven Miles*  
*City Pages, July 9, 2003*
Dan Burk, MS, JD, JSM, is the Oppenheimer, Wolff & Donnelly Professor of Law, University of Minnesota Law School. He received a JD from Arizona State University and a JSM from Stanford University. Professor Burk specializes in the law of intellectual property, with a focus on cyber law and biotechnology. He teaches in the areas of copyright, patent, and biotechnology law and is the author of numerous papers on the legal and societal impact of new technologies, including scientific misconduct, the regulation of biotechnology, and the intellectual property implications of global computer networks.

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, Cruzan 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, School of Medicine, University of Minnesota, Duluth. She serves as the Director of Clinical Research for the Department of Family Medicine, and also 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. She was a Visiting Scholar at the Hastings Center, and held a Fellowship with the Kellogg National Leadership Program. Her research interests in bioethics focus on social justice issues in healthcare settings.

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 College 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 application of consumer values 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; Staff Physician, Community-University Health Care Center (CUHCO); and Medical Director, Center for Spirituality and Healing, University of Minnesota. He received his MD from the University of Minnesota and a MTS from Harvard University Divinity School. His research interests are on the ethics of complementary and alternative medicine including pharmacoeconomics, and cross-cultural and spiritual care. Dr. Plotnikoff is on leave from the University of Minnesota while he serves as a Visiting Professor at 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.” He is also Associate Course Director for the Medical School’s introduction to clinical medicine course, “Physician and Patient.” Dr. Ratner is Immediate Past President of the American Academy of Home Care Physicians.

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 1997–1999 she was a post-doctoral 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 Assistant 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.

Visiting Scholars

Norman Berlinger, MD, PhD, Physician, Oakdale Ear Nose, and Throat, PA, Robbinsdale, MN. Dr. Berlinger’s research is 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, Out of Dark Waters: How to Recognize and Rescue a Depressed Teen (HarperCollins, forthcoming). 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 National Institutes of Health (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 forthcoming book is A Pleasing Birth: Midwifery and Maternity Care in the Netherlands (Temple University Press).

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.
Technological advances in health care and biotechnology constantly generate complex ethical issues. The Center conducts theoretical, empirical and practical research to provide scholars, professionals, policymakers, and the public with the information and understanding to confront these issues. The following is an overview of our research efforts in 2003.

Newly Funded Research

Homelessness & End of Life Care
John Song, MD, MPH, MAT, has been awarded a two-year National Institutes of Health (NIH) grant to explore the end of life (EOL) concerns and wishes of perhaps the most marginalized people in our society, those who live without the security of a home. Professor Song, along with Center colleagues Dianne Bartels, RN, MA, PhD, and Edward Ratner, MD, will conduct a qualitative investigation utilizing focus groups with several objectives including an exploration of the conceptions, concerns, and desires of homeless individuals regarding dying, EOL care and death, identification of the barriers that homeless individuals have to quality EOL care, and a description of the interpersonal relationships and communication challenges of homeless people related to these issues.

Colliding Categories: Haplotypes, Race & Ethnicity
Jonathan Kahn, JD, PhD, has been awarded a grant from the National Institutes of Health (NIH) to lead a two-year project exploring the ethical and legal issues raised by the International HapMap Project (IHP), an effort to create a haplotype map of the human genome. Center Director, Jeffrey Kahn, PhD, MPH, and Susan M. Wolf, JD, Director of the Consortium on Law and Values in Health, Environment & the Life Sciences are co-investigators on the project. Together with a working group of leading scholars from across the country they will explore the myriad ways in which two schemes of classification may collide in practice, presenting the danger that social categories of race and ethnicity will be mistaken for biological categories and thereby fuel race and ethnicity-based stigma and discrimination. This research will provide recommendations on how to handle and reconcile these social and biological classifications in the areas of medical and scientific research and practice. These recommendations together with presentations and commentary by other working group members will also be presented at a national conference to be held at the University of Minnesota in 2004.

The Center for Bioethics received funding from the US Department of Agriculture (USDA) and the National Agricultural Biotechnology Council (NABC) to host the 20th Bioethics Institute in summer of 2003. The Institute is designed to assist faculty in the life sciences and extension personnel with the integration of ethics discussions into their courses. The institute is part of a five-year collaborative grant funded by the USDA with South Dakota State University, North Dakota State University, University of Wisconsin-Madison, Iowa State University, and the University of Minnesota.

Jeffrey Kahn, PhD, MPH, was awarded a grant from the Office of Research Integrity, RCR Development Program, DHHS, for a project on “Would Your Decision on Competing Interests Pass Public Scrutiny?”; and from The Greenwall Foundation for a public education project on “Gene(sis): Contemporary Art Explores Human Genetics.”

John Song, MD, MPH, MAT, was awarded a grant from University of Minnesota’s Consortium on Law and Values in Health, Environment & the Life Sciences for a project on “Homelessness and End of Life Care”; awarded grants from the Community University Partnership in Education and Service Foundation; Edina Realty Foundation; and the Hennepin County Medical Foundation for his project “The Franklin Clinic: A Service-based Educational Opportunity.”; and is lead investigator of the University of Minnesota Medical School’s participation in the American Medical Association’s (AMA) Strategies for Teaching and Evaluating Professionalism (STEP) program.
**Ongoing Research**

**Ethnicity, Citizenship, Family: Identity After the Human Genome**

In the final year of this NIH funded project, Carl Elliott, PI, co-investigators, and project members continue to publish articles resulting from their research. Articles on identity and genetic ancestry tracing are forthcoming in 2004 in academic journals including *Developing World Bioethics*; and *Culture, Medicine and Psychiatry*.

**Genetics & Disability Insurance: Ethics, Law & Policy**

The Center was awarded a grant from the National Human Genome Research Institute (NHGRI) in 2000 for a project entitled “Genetic Testing and the Future of Disability Insurance: Ethics, Law & Policy,” with Jeffrey Kahn acting as principal investigator and Susan M. Wolf as co-investigator. Now near completion, the project convened an interdisciplinary working group of experts to address issues that will arise in the use of genetic information in the context of disability insurance. Insurance companies are increasingly interested in genetic information to help determine eligibility and premium rates. While the idea of genetic testing has been discussed in the context of life and health insurance, the impact this testing will have on disability insurance is an issue that has not been explored in-depth. The project hosted a conference in 2003 to engage the public in a discussion of the ethical, legal, and policy issues raised by the use of genetic testing in disability insurance. The project’s final products will be the publication of a white paper authored by the working group, as well as a journal symposium issue devoted to articles based on the conference proceedings.

**Nurses: Research Integrity in Clinical Trials**

Joan Liaschenko, RN, PhD, and co-investigators Debra DeBruin, PhD, and Anastasia Fisher, RN, DNSc, have completed the data collection phase of their study of the ethical issues encountered by nurses working in clinical trials. This study funded by the National Institute of Nursing Research (NINR), 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. Liaschenko, DeBruin and Fisher are proceeding with data analysis, and examining the implications of their findings for the responsible conduct of research. They plan to present their results in a number of venues, including the US Office of Research Integrity’s Conference on Research Integrity in San Diego, CA, in November 2004.

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

“Consortium to Address Social, Economic, and Ethical Aspects of Biotechnology” with South Dakota State University—funded by the United States Department of Agriculture.

“Genetic & Environmental Determinants of Triglycerides” with the Division of Epidemiology, School of Public Health—funded by the National Institutes of Health.

“International Bioethics Education and Career Development Award” with the Department of Sociology—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.

“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.

“Promoting Responsible Conduct of Research” with the American Association of Bioethics and Humanities—funded by the American Medical Association.

“Research Experiences for Undergraduates in the Biological Sciences” with the College of Biological Sciences, University of Minnesota—funded by the National Science Foundation.

“Training for Future Biotechnology Development” with the College of Biological Sciences, University of Minnesota—funded by the National Institutes of Health.

“What we hope to do long-term is evaluate policies and procedures to see whether they really are adequate. It's just very striking when you look at literature and research ethics. The voices of nurses are absent.”

Debra DeBruin
Center faculty continue leadership in the field of bioethics with publications in books, book chapters, articles in professional journals, on-line media, and commissioned reports.

**Books**


**Book Chapters**


**Publications**


**Articles**


“**It is imperative that we figure out how to use these new genetic categories constructively and responsibly because this information is very powerful.**”

Jonathan Kahn
On the National Institutes of Health (NIH) funded project exploring the ethical and legal issues raised by the International HapMap Project (IHP).

*Pictures of Health*, Autumn 2003
Liaschenko J. Ethics, Gender, Disciplines and the Social Division of Labor. *Nursing Ethics* 2003;10(2):161-164.


Ratner E. The Answer is Home Care, But What is the Question? *Minnesota Physician* 2003.


Reviews


Abstracts


Bebeau M. The Professional Role Orientation Inventory (PROI) and PROI-PT. Paper presented at International Meeting of the Association of Moral Education. July 17-20, 2003, Krakow, Poland.

Online Publications


Reports

Bioethics Examiner

In 2003, the Center for Bioethics published three volumes of the Bioethics Examiner bringing the most up-to-date issues in bioethics to more than 8,500 readers worldwide.

The Fate of Dignity in the World of Gene Patents, by Jonathan Kahn, JD, PhD; Winter 2003 (Vol. 6, Issue 4).

Changing Our Priorities in Organ Distribution, by Maryam Valapour, MD; Spring 2003 (Vol. 7, Issue 1).

Children as Research Subjects: Guinea Pigs or Therapeutic Orphans?, by Carol Tauer; PhD; Fall 2003 (Vol. 7, Issue 2).

Guides/Manuals


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:

Accountability in Research
American Journal of Bioethics
American Journal of Managed Care
American Journal of Public Health
Annals of Epidemiology
Archives of Family Medicine
Archives of Internal Medicine
Bioethics
British Medical Journal
Cambridge Quarterly of Health Care Ethics
Christian Scholar's Review
Community Genetics
Cornell University Press
The Counseling Psychologist

Current Research on Occupations and Professions
Developing World Bioethics
Encyclopedia of Ethics, Legal and Policy Issues in Biotechnology
Ethnicity and Medicine
Family Medicine
Genetics in Medicine
Hastings Center Report
Illness, Crisis, and Loss
IRB: Ethics & Human Research
Journal of the American College of Dentists
Journal of the American Dental Association
Journal of American Geriatrics Society

Journal of the American Medical Association
Journal of Cancer Education
Journal of Clinical Ethics
Journal of Dental Research
Journal of Ethics, Law, and Aging
Journal of Family Practice
Journal of General Internal Medicine
Journal of Genetic Counseling
Journal of Health Care for the Poor and Underserved
Journal of Health Politics, Policy and Law
Journal of Law, Medicine and Ethics
Journal of Moral Education
Journal of Philosophy, Science & Law
Journal of Urban Health
Journal of Urban History
Jurimetrics
Kennedy Institute of Ethics Journal
Lancet
Milbank Quarterly
National Endowment for the Humanities
National Human Genome Research Institute, National Institutes of Health (NIH)
National Institutes of Health (NIH)
New England Journal of Medicine
New Zealand Journal of Bioethics
Oxford University Press
PERQ (Professions Education Research Quarterly)
Philosophy, Psychiatry and Psychology
Qualitative Sociology
Science and Engineering Ethics
Social Problems
Social Science and Medicine
Social Science History
Sociology of Health and Illness
Teaching and Learning in Medicine
Theoretical Medicine
Virtual Mentor, American Medical Association
Women and Health
Education

The Center for Bioethics offers a broad range of courses, 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 2003.

Philosophy
All students enrolled in the Graduate Minor in Bioethics are required to take a course in biomedical ethics, offered through the Department of Philosophy. 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. In addition, Professor Carl Elliott 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
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 is passionate about teaching and her philosophy of teaching reflects her style in the classroom. She starts where students are but encourages and challenges them to critique the moral understandings of health care in general and the particular clinical geographies in which they practice or conduct research.

Public Health (courses are 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 United States 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
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

This annual course offered through the Law School, 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 course, which is open to upper-class 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 is the Center’s Director for Medical Ethics Education. He directs ethics education for undergraduate 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. Professors Steven Miles and John Song provide independent study courses in ethics through the Department of Medicine.

Dr. Song serves on several educational committees in the Medical School representing 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 evaluator 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.

College of Biological Sciences

Ethics Component: Research Experiences for Undergraduates in Molecular Biology

This is the fifth year the Center for Bioethics has worked with the College of Biological Sciences (CBS) to provide a four session course on ethics in research for undergraduates enrolled in the CBS Life Sciences Summer Undergraduate Research Program. The course is designed to familiarize students with current issues in bioethics, present various approaches to resolving ethical dilemmas and explore the strengths and limitations of these approaches, and to provide students with the skills to apply moral reasoning to research that presents ethical conflicts. This project is funded by the National Science Foundation.

Graduate Opportunities in Bioethics

The Center for Bioethics continues its success in attracting 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 expanding their knowledge in 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 and second, 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.

**Postdoctoral Fellowship**

The Center offers an annual postdoctoral fellowship for scholars who have completed the PhD or other relevant terminal degree in any discipline related to bioethics. The fellowship has proven to be very instrumental for postdoctoral trainees in pursuing a career in the field of bioethics.

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

- Anth 1003/1003V Understanding Cultures
- CSpH 5315 Traditional Tibetan Medicine: Ethics, Spirituality, and Healing
- GCD 8913 Psychosocial Issues in Genetic Counseling
- GCD 8914 Ethical and Legal Issues in Genetic Counseling
- Law 6824 Genetics and Law
- Law 6875 Seminar: Law, Health and Life Sciences
- MED 7598 Biomedical Ethics
- MED 7599 Bioethics Theory
- NURS 4101 Ethical Sensitivity and Reasoning in Healthcare
- NURS 8140 Moral and Ethical Positions in Nursing
- Phil 8320 Seminar in Medical Ethics: Wittgenstein and Ethics
- POL 1001,003 American Democracy in A Changing World
- PubH 5741 Ethics in Public Health: Professional Practice and Policy
- PubH 5742 Ethics in Public Health: Research and Policy
- PubH 8803 Long-Term Care: Principles, Programs, and Policy

**Lectures in University of Minnesota programs include:**

- Biomedical Engineering Seminar
- Biostatistics
- Boynton Health Center Medical Staff
- Cancer Center Bone Marrow Transplant Seminar
- Carlson School of Management
  - Health Administration
  - Justice in Healthcare
- Center for German and European Studies
- Center for Victims of Torture
- CHIP Student Committee on Bioethics Lecture Series
- College of Biological Sciences
- Educational Psychology Research Methods Course
- Elder Learning Institute
- Epidemiology Division, School of Public Health
- Fairview University Medicine House Staff Conference
- Hennepin County Medical Center Grand Rounds
- Law School
- Joint Degree Program in Law, Health & the Life Sciences
- Multicultural Summer Research Opportunities Program
- Medical School
  - Internal Medicine
  - Medicine Grand Rounds
  - Morbidity & Mortality Conference
  - “On Doctoring” Series
  - Physician and Society
  - Lung Transplant Medical Residents
- Minnesota Medical Foundation Medical School Alumni Day
- Responsible Conduct of Research
- School of Dentistry
- School of Nursing
  - Nurse Practitioner Program
  - Senior Nursing Program on End of Life
- Summer Scholars Program, Duluth campus
- University Undergraduate Research Opportunities Program
- Veterinary Medicine
- Veterans Administration Infectious Disease Intercity Conference
The Center 2003 lecture series on topics in bioethics included:

“American Medicine Meets the American Dream” by Carl Elliott, MD, PhD, Director of Graduate Studies, Center for Bioethics; Associate Professor, Department of Pediatrics; Department of Philosophy, University of Minnesota.

“Health Care and International Financial Organizations” by Steven Miles, MD, Professor, Center for Bioethics; Department of Medicine, University of Minnesota Medical School.

“Genetic Determinism and Criminal Behavior: Why Biologists Need Sociology 101” by Robert Dingwall, PhD, Professor, School of Sociology and Social Policy; Director, Institute for the Study of Genetics, Bio-risks and Society, The University of Nottingham.

“The Ethics of Professional Rivalry: Midwives and Obstetricians in the Netherlands and the United States” by Raymond deVries, PhD, Visiting Faculty, Center for Bioethics, University of Minnesota; Professor, St. Olaf College.

“Where Are We Going in the Human Genome Project?” by Jeffrey Kahn, PhD, MPH, Director, Center for Bioethics; Mass Family Chair in Bioethics.

“Psychiatry and Feminist Virtue Ethics” by Andrea Nicki, PhD, Post-Doctoral Fellow, Center for Bioethics, University of Minnesota.

“End of Life Care and Homelessness” by John Song, MD, MAT, Assistant Professor, Center for Bioethics; Department of Medicine, University of Minnesota Medical School.

Co-sponsored seminars

CHIP Student Committee of Bioethics Winter Lecture Series
“Financial Recruitment Incentives in Research” by Trudo Lemmens, LLM, Assistant Professor, Faculties of Law and Medicine, University of Toronto.

Hennepin County Medical Center Bioethics Committee Seminar
“Long Goodbye: The Deaths of Nancy Cruzan” by William Colby, Fellow, Midwest Bioethics Center.

The Weisman Art Museum presentation and panel discussion
“ART + GENOMICS + ETHICS” by speaker Robin Held, Curator, Henry Art Gallery, University of Washington with panelists Evelyn Fox Keller, PhD; Eduardo Kac, Artist; Jeffrey Kahn, PhD; and Helen Longino, PhD.

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

“Medical Devices: A Different Twist on the Ethics and Law of Research Protections” by E. Haavi Morreim, PhD with commentators Ken Liebman, Esq., Susan Foote, PhD.

“Solutions to the Crisis in Human Subjects Research: From Pillar to Post?” by Jeremy Sugarman, MD, MPH, MA, with commentators Jeffrey Kahn, PhD, MPH, and Cathy Jordan, PhD.

Lunch Series on the Societal Implications of the Life Sciences

“Globalization and Biodiversity” by David Ehrenfeld, MD, PhD.

“Poverty, Pollution & Public Health: Strategies for Building Just and Sustainable Communities” by Robert Bullard, PhD.

“Science, Ethics, and the Animal Protection Movement” by Dale Jamieson, PhD.

“Shifting Visions of Disability: Public Health, Law & Ethics” by Wendy Parmet, JD.

The Bioethics Institute 2003

The University of Minnesota Center for Bioethics hosted the 20th in a series of institutes held around the world. The five day institute is cosponsored and funded by the United States Departments of Agriculture (USDA), and the National Agricultural Biotechnology Council (NABC). The institute is designed to provide extension personnel and faculty in the biological, agricultural, and environmental sciences with the background they need to incorporate bioethics into their courses and extension activities. The institute is in collaboration with Iowa State University, North Dakota State University, South Dakota State University, and the University of Wisconsin, Madison.
Throughout its history, the Center has been recognized for its effort to bring bioethics to the attention of the public. The following reflects our outreach activities in 2003.

Resource Center

Supported by the Starr Foundation

In its second year, the Resource Center has expanded efforts in making cutting edge research available to students of all levels, to the general public, and to healthcare faculty and professionals who serve the public. We have responded to requests from the community and made ethics educational resources widely available through educational materials and web based materials as well as personal responses to email and phone inquiries.

Resource Center staff provided assistance in locating literature, videotapes, websites, and forms, and in developing topical bibliographies for research or educational purposes. We assisted with finding speakers to present at meetings and conferences, conducted informational interviews, and acted as a liaison between Center professionals and the press. Resource requests came from a broad range of people throughout the country for information on topics including ethical issues in cloning, euthanasia, genetics, stem cell research, and clinical ethics.

In response to a needs assessment survey in year one, two new publications were developed; *Human Stem Cells: An Ethical Overview* a bioethics overview tailored for those who desire a basic understanding of the current ethical issues involved in stem cell research; and *A Guide to Research Ethics* in response to a large number of requests from the University research and teaching faculty for materials on this topic. The overview on *Ethics of Organ Transplantation* was updated with the most current information available. These publications are available on our website at www.bioethics.umn.edu.

Currently, Resource Center staff are working on a survey for other groups throughout Minnesota, such as chaplains, teachers, healthcare professionals, and legal professionals who might benefit the most from resources in bioethics. We plan to conduct more detailed analysis on an earlier survey on the needs of the students, faculty, and community members. Based on our assessment of these surveys we will continue to develop new educational materials on topics such as transplantation, assisted reproductive technologies, and end of life. We will update existing bioethics overviews on resource allocation, and human genetics.

Resource Center staff will focus its attention on using the Center for Bioethics’ website as a tool for distributing information and making resources more accessible, since survey responses have indicated that this is the preferred method. We will work to expand the audience who can utilize these resources by marketing to them, to professional audiences, and public education outlets.

The Minnesota Network of Institutional Ethics committee

Resource Center staff continued to support the efforts of the Minnesota Network of Healthcare Ethics Committees (MNHEC) to host workshops, develop programs and policies, and to generate and distribute educational materials to its members throughout Minnesota and in Wisconsin. MNHEC’s members represent acute care facilities, state medical facilities, board and care homes, long-term care facilities, a state guardianship agency, and an ethics center. We cosponsored a day long conference on “Medical Futility: How Much is Too Much?” with the St. Croix Valley Health Care providers Ethics Advisory Committee. MNHEC discontinued membership and activities at the end of 2003 due to lack of funding. The Bioethics Resource Center continues to host the listserv on which members discuss the challenges they face every day in their health care facilities.

The Phillips Neighborhood Clinic

John Song, MD, MPH, MAT, and Eric Meininger, MD, direct the new Phillips Neighborhood Clinic recently opened by the University of Minnesota during “National Cover the Uninsured Week.” The clinic is a partnership between the University of Minnesota Academic Health Center, the Community-University Health Care Center, the Center for Health Interdisciplinary Programs, and the Oliver Presbyterian Church. The clinic provides high-quality, affordable and, in many cases, free-health care to uninsured and underinsured people living in the Phillips Neighborhood of Minneapolis, with a focus on those who are homeless. No one is denied care for lack of ability to pay. Dr. Song founded the project three years ago, and with the help of enterprising and dedicated medical, physical therapy, pharmacy, nursing, and public health students from throughout the Academic Health Center, the clinic opened its doors in March 2003.
Center Sponsored Conferences

Genetics and Disability Insurance: Ethics, Law & Policy Conference

The Center for Bioethics and the Joint Degree Program in Law, Health, & the Life Sciences held a day-long conference to address the understanding of ethical, legal, and policy challenges arising in disability insurance as a result of emerging genetic technologies. Topics included: Disability in the Genetic Age; Disability Insurance: Predictive Medical Information and Underwriting; The Moving Target of Disability; Genetic Exceptionalism, Privacy, and Confidentiality; and Health, Life and Disability Insurance: Understanding the Relationships. Information from this conference will be published in a special supplement forthcoming in *Journal of Law Medicine & Ethics* in 2004.

The Bioethics Institute for Life Science Faculty

The Bioethics Institute sponsored by the United States Departments of Agriculture (USDA) and the National Agricultural Biotechnology Council (NABC) is a unique annual conference devoted to faculty in the life sciences and extension personnel. The Institute is designed to assist with the integration of ethics discussions into their courses. The twentieth in a series of Institutes that have been held around the world, was hosted by the Center for Bioethics on the University of Minnesota campus. More than 35 people from across the nation joined together for this five day institute which included a field trip to the Cedar Creek Natural History Area — a National Science Foundation long-term ecological research site in Bethel, Minnesota. For information on the institute and future institutes, visit the Center website at www.bioethics.umn.edu.

Other Events

The Center for Bioethics and the University of Minnesota Bookstores held book signings and discussions with Steven Miles, MD on his new book *The Hippocratic Oath and the Ethics of Medicine*; and with Carl Elliott, MD, PhD, on his new book *Better Than Well: American Medicine Meets the American Dream*.

Co-sponsored conferences in 2003

“Responding to Controversies: Using Organizational Ethics in Healthcare” co-sponsored with the University of Minnesota Center on Aging; Minnesota Hospital Association; Minnesota Medical Association; Minnesota Center for Healthcare Ethics; and the Minnesota Home and Housing Alliance.

“Integrity and Accountability in Clinical Research” co-sponsored with the National Patient Safety Foundation (NPSF).

“Gene(sis): Contemporary Art Explores Human Genomics” exhibit and lecture series. Co-sponsored with the Humanities Institute; College of Liberal Arts; and the Weisman Art Museum.

University of Minnesota Consortium on Law and Values in Health, Environment & the Life Sciences symposia

“Revamping the Law on Assisted Reproduction: from IVF to Surrogate Motherhood.” Speakers included: Alan DeCherney, MD, Professor, UCLA OB/GYN and Editor, Fertility and Sterility; John Robertson, JD, Vinson & Elkins Chair, University of Texas, School of Law; Rep. Kathy Tingelstad, Minnesota House of Representatives; Sean Tipton, Director of Public Affairs, American Society for Reproductive Medicine; Daonna Depoister, President, RESOLVE of Minnesota; Carol Tauer, PhD, Professor Emeritus of Philosophy, College of St. Catherine; Lisa Erickson, MD, Center for Reproductive Medicine; David Ball, PhD, Reproductive Medicine and Infertility Associates; Tom Prichard, JD, MPP, President, Minnesota Family Council; Deborah Simmons, PhD, Reproductive Medicine and Infertility Associates, Partners in Psychiatry and Psychology; Steven Snyder, JD, Snyder Law Office; and Moderators Susan Wolf, JD, Chair, Consortium on Law and Values in Health, Environment & the Life Sciences and Jeffrey Kahn, PhD, MPH, Director, Center for Bioethics.

“The Limits of Personal Privacy: Biomedical Information in Public Health, Population Genomics, and Mass Disasters.” Speakers included: George Annas, JD, MPH, Chair, Health Law, Boston University; Janlori Goldman, JD, Director, Health Privacy Project, Washington DC; Larry Gostin, JD, LLD, Professor of Law, Georgetown University; Professor of Public Health, Johns Hopkins University; Director, Center for Law & the Public’s Health; Kathy Hudson, PhD, Director, Genetics and Public Policy Center, Johns Hopkins University; and Mike Hatch, JD, Minnesota Attorney General.
Faculty Service on University of Minnesota Committees and Boards

Advisory Committee for Research and Grants Management Education
Blood Borne Disease Policy Committee, Medical School
Center for Holocaust and Genocide Studies Advisory Board
Community University Partnership in Education and Service Board
Consortium on Law and Values in Health, Environment, & the Life Sciences Executive Committee
Faculty Education Advisory Committee on Responsible Conduct of Research
Genetic Counseling Graduate Program Admissions Committee
Genetics/Genomics Integration Work Group, Medical School
Human Subjects Review Committee, Center for Victims of Torture
Joint Degree Program in Law, Health & the Life Sciences, Law School, Governing Committee
Law School Committee on Interdisciplinary Appointments and Joint Degree Programs
MD/PhD Program Steering Committee, Medical School
On-Doctoring Program Steering Committee, Medical School
Physician and Patient Curriculum Committee, Medical School
Physician and Patient Steering Committee, Medical School
Physician and Society Curriculum Committee, Medical School
Physician and Society Steering Committee, Medical School
Primary Education Committee, Medical School
Public Health Certificate in Core Concepts Advisory Committee
Research Ethics Advisory Committee
School of Dentistry, Promotion and Tenure Committee
Senate Research Committee
Silha Center for the Study of Media Ethics and Law Advisory Committee
Stem Cell Ethics Advisory Board
Student Committee on Bioethics, Council on Health Interdisciplinary Participation, Medical School

Faculty Service on State and National Boards and Committee Memberships

Advanced Cell Technology Ethics Advisory Board
American Association of Law Schools Section on Intellectual Property
American Board of Genetic Counseling
American Educational Research Association Awards Committee
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 Board of Directors
American Society of Law, Medicine and Ethics Board of Directors
Association for Moral Education Awards Committee
Brookdale Foundation National Fellowship Program
Center to Advance Palliative Care, Robert Wood Johnson Foundation
LifeSource (OPO) Medical Ethics Advisory Committee
Long Island Breast Cancer Study Project (LIBCSP), NCI, Oversight Committee for the Geographic Information System (GIS)
Minnesota Asian American Health Coalition
Minnesota Association for Human Genetics
Minnesota Center for Victims of Torture Institutional Review Board
National Academy for State Health Policy, Long-Term Care Committee
NHGRI Special Emphasis Panel: Ethical, Legal, and Social Implications of Genetics, NIH
Save the Minneapolis Libraries Committee
Urban Coalition Health Advisory Board
Volunteers of America
Walker Care Corporation Board

“We all have a responsibility to promote the health of our neighbors. This responsibility is even greater for those of us who work and learn at a publicly funded University.”

John Song
Founder and Medical Director of the Phillips Neighborhood Clinic
Pictures of Health, Spring 2003
Center faculty presented their work and delivered lectures in a variety of public settings:

<table>
<thead>
<tr>
<th>Local and Regional Presentations</th>
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<tr>
<td>4th Annual Cutting Edge Conference “New Frontiers in Transplantation”</td>
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<tr>
<td>Fairview University Medical Center Minneapolis, MN</td>
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<td>Allina Conference on the Physician as Steward of Resources Minneapolis, MN</td>
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<td>American Association of Critical Care Nurses Minneapolis, MN</td>
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<td>American Association of University Women Minneapolis, MN</td>
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<td>Augsburg College Physician Assistant Program Minneapolis, MN</td>
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<td>Carleton College Program on Ethical Reflection Northfield, MN</td>
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<td>Cover the Uninsured Week Town Hall Meeting St. Paul, MN</td>
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<td>DFL Education Fund Health Care Reform Minneapolis, MN</td>
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<td>Eden Prairie High School Health Careers Eden Prairie, MN</td>
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<td>Fairview Southdale Hospital Grand Rounds Edina, MN</td>
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<td>Fairview University Medical Center Annual Conference Minneapolis, MN</td>
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<td>Fairview University Medical Center Social Work Rounds Minneapolis, MN</td>
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<td>First Unitarian Society of Minneapolis Minneapolis, MN</td>
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<td>Friendship Village Bloomington, MN</td>
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<td>Hamline University School of Law Minneapolis, MN</td>
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<td>Jewish Community Center of St. Paul Resilience in Aging St. Paul, MN</td>
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<td>Long-term Care Directors Ethics Committee Mankato, MN</td>
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<td>Lung Transplant Support Group Minneapolis, MN</td>
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<td>Medical Technology Leadership Forum Minneapolis, MN</td>
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<td>Minneapolis Society of Internal Medicine Fall Event Minneapolis, MN</td>
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<td>Minneapolis-University Rotary Club Minneapolis, MN</td>
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<td>Minnesota Community and Technical College International Studies Students Minneapolis, MN</td>
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<td>Minnesota Department of Health Lunch Series St. Paul, MN</td>
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<td>Minnesota International Center Seminar with Senior Moldovan Physicians Minneapolis, MN</td>
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<td>Minnesota Valley Unitarian Universalist Fellowship Minneapolis, MN</td>
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<td>National Alliance for the Mentally Ill Minneapolis, MN</td>
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<td>Odyssey Group Interlachen Country Club Minneapolis, MN</td>
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<td>Park Nicollet Institute Contemporary Issues in Clinical Research St. Louis Park, MN</td>
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<td>Park Nicollet Institute Symposium on Research Ethics St. Louis Park, MN</td>
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<td>Robert Wood Johnson Foundation Cover the Uninsured Week St. Paul, MN</td>
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<td>St. Joseph’s Hospital 150th Anniversary Event St. Paul, MN</td>
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<td>Thomson University Eagan, MN</td>
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<td>Universalist Church Excelsior, MN</td>
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<td>Veterans Administration Medical Center Seminar Series Minneapolis, MN</td>
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<td>Women’s Club of Minneapolis Minneapolis, MN</td>
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*Jeff Kahn and Deb DeBruin at Bioethics Institute 2003*
National and International Presentations

4th Annual Meeting of the Association of Internet Researchers
Toronto, CANADA

5th Annual Evolving Science of Blood/Marrow Transplantation Conference
United Resource Network
New Orleans, LA

9th Annual Teaching Survival Skills and Ethics Conference
Snowmass, CO

44th Annual Meeting of the American Society of Hematology
San Diego, CA

American Bar Association/Section of Science and Technology Law Conference
Chapel Hill, NC

American Geriatrics Society/AAHCP Annual Meeting
Baltimore, MD

American Medical Directors Association Annual Meeting
Orlando, FL

American Public Health Association/131st Annual Meeting and Exposition
San Francisco, CA

American Society of Bioethics and Humanities and the Canadian Bioethics Society Joint Annual Meeting
Montreal, CANADA

American Society for Blood and Marrow Transplantation Society Annual Conference
Keystone, CO

American Trial Lawyers Association
Washington, DC

Annual Conference of the Law & Society Association
Pittsburgh, PA

Association of American Medical Colleges Group on Institutional Advancement
National Professional Development Conference
Memphis, TN

Association for Practical and Professional Ethics Annual Meeting
Charlotte, NC

Bioethics and the Health Professions Conference
Lake Louise, CANADA

British Sociological Association Medical Sociology Group Annual Meeting
York, ENGLAND

Bulgarian Medical Academy Institute of Social Medicine
Soﬁa, BULGARIA

Chicago International Center for Health Leadership Development Workshop
Chicago, IL

City of Hope National Medical Center International Symposium on Umbilical Cord Blood Transplantation
Monrovia, CA

Columbia Law School Physician-Assisted Suicide Seminar
New York, NY

Committee on the Use of Third Party Toxicity Research with Human Participants
Washington, DC

Cornell Law School Faculty Workshop
Ithaca, NY

Evolving Science of Blood/Marrow Transplantation United Network Organization Sharing Annual Conference
New Orleans, LA

First International Conference on Bioethics and Biolaws
Copenhagen, DENMARK

Georgetown University Law Center Intellectual Property Symposium
Washington, DC

Harvard Medical School
Boston, MA

Heartland Home Health Care and Hospice Leadership Meeting
Orlando, FL

The Ian Ramsey Centre Hastings Centre Consultation
Windsor Castle, ENGLAND

Instituto Scientiﬁco San Raffaele International Colloquium on Science and Ethics
Milan, ITALY

Integrity and Accountability in Clinical Research Conference
National Patient Safety Foundation
Washington, DC

International Meeting of the Association for Moral Education
Krakow, POLAND

International Society for Heart & Lung Transplantation
Vienna, AUSTRIA

International Workshop on Ethics and Bioethical Problems in Contemporary Society
Siena, ITALY

Johns Hopkins University Brin Lecture
Baltimore, MD

Johns Hopkins University Phoebe Berman Bioethics Institute Greenwall Fellowship Program
Baltimore, MD

LTA Symposium on the Past, Present, and Future of the Federal Circuit
Case Western Reserve University School of Law
Cleveland, OH

Marquette University School of Law Helen Nies Memorial Lecture
Milwaukee, WI

The McCain Annual All Service Academy Ethics Conference
US Naval Academy
Annapolis, MD

Mt Holyoke College Public Lecture
South Hadley, MA

National Academy of Sciences Food Forum Symposium
Washington, DC

National Institutes of Health Deep Brain Stimulation Consortium Meeting
Washington, DC

National Institutes of Health National Cancer Institute Summer Curriculum in Cancer Prevention
Rockville, MD

National Institutes of Health Office of Research on Women’s Health
Washington DC

Newcastle Medical School Ethics Case Teaching
Newcastle, ENGLAND

Princeton University Center for Human Values Decamp Seminar
Princeton, NJ

Princeton University Maclean Lecture
Princeton, NJ

Project on Death in America
New York, NY

Remington Report Home Care Executives Meeting
San Diego, CA

Science, Technology, and Law Program of the National Academies
Washington, DC

Society for the Social Studies of Science Annual Meeting
Atlanta, GA
Is ugliness a disease? New medical treatments for ‘conditions’ such as short stature or anxiety are sweeping America. But it’s society, not the patient, which is ill.”

Carl Elliott
Media Appearances

Print Media
AHC Community News
AHC Pictures of Health
American Medical News
Associated Press
ASH News Daily
Baltimore Sun
Boston Globe
Boston Herald
Capital Reports
Center for Investigative Reporting
Chicago Tribune
Choice In Dying
Chronicle of Higher Education
City Pages
Copley News Service
Discover Magazine
Duluth News Tribune
Family Therapy Magazine
Grand Forks Herald
The Guardian (UK)
IRB Reporter
The Forum
The Kansas City Star
London Financial Times
London Times
Los Angeles Times
Minneapolis Star Tribune
Minnesota Daily
Minnesota Magazine
Minnesota Medicine
Minnesota Monthly
Minnesota News Network
Mpls St. Paul Magazine
MSN Slate Magazine
Nature
New York Daily News

Online Media
AHC News Capsules
Amednews.com
Greenhouse Project E-Report
MSNBC News
New York Times
University of Minnesota Brief
WebMD

Radio and Television
Bill Nye the Science Guy
CNN Live
Fox 9 News
KARE 11 News
KSTP Channel 5 News
Minnesota News Network
Minnesota Public Radio
National Public Radio
NBC TV
Science Friday
WCCO Radio
WCCO TV
WOR Radio New York
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