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, as well as contributing to bioethics on the national and international levels. We continue to work hard to attract new sources of extramural funding for Center-based research and projects, and to broaden our teaching efforts throughout the Academic Health Center and across the University.

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.

Our success depends in large part on those who support our efforts. For many years, the Center has turned to a community-based Center Advisory Board (CAB) for advice and counsel. The Center’s evolution, maturation and organization within the University limited the importance of the CAB, and in late 2002 we held its final meeting. We thank the members for their input and support, and trust they will continue in their roles of “friends of the Center.” In addition, the Center’s efforts depend on funding for our research and programs, and it is important to mention our contributors by name: the University’s Academic Health Center, The Starr Foundation, Dorsey & Whitney, LLP, The Greenwall Foundation, the National Institutes of Health, and in our 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 on our efforts.

Jeffrey Kahn, PhD, MPH
Director, Center for Bioethics
Faculty News, Appointments and Awards

Dianne Bartels, RN, MA, PhD, was appointed as a Research Scholar in the Center for Bioethics, University of Minnesota; Examining Member in the Graduate School, University of Minnesota; and member of the Data and Safety Monitoring Board, University of Minnesota Cancer Center.

Muriel Bebeau, PhD, was awarded a sabbatical leave for the 2002-03 year to conduct research on moral identity measures and on moral exemplars. She will also finish a book *License to Care: Inspiring Stories of Motivation and Commitment*. Professor Bebeau will be a visiting professor at the US Military Academy at West Point, NY, to redesign the Academy's character development program and design a measure of ethical concepts.

Norman Berlinger, MD, PhD, was appointed as Visiting Scholar in the Center for Bioethics, University of Minnesota; and appointed to the Biomedical Ethics Committee at North Memorial Hospital, Robbinsdale, MN.

Dan Burk, JSM, JD, was appointed as Visiting Professor in Management in the Network Economy at Universita Cattolica del Sacro Cuore, Italy; appointed as Oppenheimer, Wolff & Donnelly Professor of Law; and Chair, Section on Intellectual Property, American Association of Law Schools.

Debra DeBruin, PhD, was appointed to the National Marrow Donor Program (NMDP) Institutional Review Board (IRB).

Barbara Elliott, PhD, was named 2002 Researcher of the Year by the Minnesota Academy of Family Physicians.

Carl Elliott, MD, PhD, was appointed to the faculty of the graduate minor in Studies in Science and Technology, University of Minnesota; and awarded a Visiting Professorship at The Institute for Advanced Study, in Princeton for one year beginning July 2003.

Jeffrey Kahn, PhD, MPH, was appointed to the Board of Directors for the American Society for Law, Medicine, and Ethics (ASLME); the Editorial Board for the *Journal of Law, Medicine, and Ethics* (JLME); and to the Governing Board of the University of Minnesota Center for Global Health.

Jonathan Kahn, JD, PhD, was appointed as Research Scholar, 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.

Bonnie LeRoy, MS, was appointed Associate Professor, Department of Genetics & Cell Biology & Development, University of Minnesota.

Joan Liiaschenko, PhD, was appointed as Adjunct Associate Professor in the Faculty of Nursing at the University of Toronto; and as Visiting Scholar in the Department of Nursing at Hokkaido University, Sapporo, Japan.

Anna Mastroianni, JD, MPH, was appointed as program committee Co-chair for the joint meeting of the Section of Science and Technology Law, American Bar Association, and the American Association for the Advancement of Science.

David Mayo, PhD, was awarded a sabbatical leave for the 2002-03 academic year to study the ethics of “speaking for others,” and the political and ethical debate over physician aid-in-dying.

Steven Miles, MD, was recertified by the American Board of Internal Medicine in Geriatric Medicine.

Andrea Nicki, PhD, was awarded the 2002-03 Post-Doctoral Fellowship in the Center for Bioethics.

Greg Plotnikoff, MD, MTS, is on leave from the University of Minnesota until 2005 while he serves as a Visiting Professor of Medicine at Keio University Medical School, Tokyo, Japan.

Maryam Valapour, MD, was appointed as Assistant Professor in the Center for Bioethics, and the Division of Pulmonary, Allergy and Critical Care Medicine, Department of Medicine, University of Minnesota Medical School.
Center Faculty

Jeffrey Kahn, PhD, MPH, is the Center’s Director. He is also a Professor in the Department of Medicine, University of Minnesota Medical School; Division of Health Services Research and Policy, School of Public Health; and Department of Philosophy. Professor 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.

Professor Kahn is currently Principal Investigator along with Susan M. Wolf, JD, on a project entitled “Genetic Testing and Disability Insurance: Ethics, Law, and Policy,” funded by the National Institutes of Health. Professor Kahn is Co-Chair of the Association of Schools of Public Health Curriculum Development Project in Ethics and Public Health. Kahn's current research areas include ethics in research on human subjects, ethics of stem cell research and related technologies, and ethics and public health. He is the author of numerous books, journal articles, and book chapters.

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Dianne Bartels, RN, MA, PhD, is the Center’s Associate Director and adjunct faculty member in the School of Nursing, University of Minnesota. She has a Master's degree in Psychosocial Nursing Program from the University of Washington and a PhD in Family Social Science from the University of Minnesota. Her recent research and publications have focused on the ethics of genetics in health care, and care of patients and families at the end of life. She is currently working on ethics and genetics, and ethical issues in end of life care.

Debra DeBruin, PhD, is Assistant Professor, 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, Department of Pediatrics, University of Minnesota Medical School; and Department of Philosophy. Dr. Elliott holds a MD from the Medical University of South Carolina and a PhD in philosophy from the University of Glasgow (Scotland). He is currently Principal Investigator on a project entitled “Ethnicity, Citizenship, Family: Identity After the Human Genome Project,” funded by the National Institutes of Health. Professor Elliott is working on a collection of essays currently in-press, edited with Tod Chambers, Prozac as a Way of Life (UNC Press); and Better Than Well: American Medicine Meets the American Dream (Norton 2003). He is the author of numerous other books, journal articles, and book chapters.

“With your outstanding faculty and students, the Center continues to expand its timely programs of research, education and public information that are critical not only to advancement of science, but that are also essential to improving the health care and quality of life for our citizens. Keep up the great work.”

-Johnathan Kahn, JD, PhD, is Research Scholar, 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. 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. He is currently exploring 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.

-Jonathan Kahn, JD, PhD, is Research Scholar, 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. 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. He is currently exploring 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. She is also Adjunct Associate Professor of Nursing at the University of Calgary, Canada and an Associate to the International Centre for Nursing Ethics at the University of Surrey, England. Dr. Liaschenko holds a PhD in nursing from the University of California, San Francisco where she also did postdoctoral work. She is co-author of Ethical Dilemmas and Nursing Practice, 4th edition (Appleton and Lange, 1997) and co-editor of the journal, Nursing Philosophy. Her research interests are in the moral dimensions of nursing work, feminist ethics, and humanities and nursing.

Steven Miles, MD, is Professor in the Center for Bioethics; and Professor, Department of Medicine and Geriatrics, University of Minnesota Medical School. He is a recipient of the Distinguished Service Award from the American Society for Bioethics and the Humanities, and a Fellow of the American College of Physicians. He received his MD from the University of Minnesota and did postgraduate work at United Theological Seminary. His areas of interest include the ethics of health care for homeless persons, HIV/AIDS care, 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. He 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.

Dan Burk, MS, JD, JSM, is Professor, University of Minnesota Law School. He received an MS in Molecular Biology and Biochemistry from Northwestern University; 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 in the Department of Neurology, Hennepin County Medical Center, Minneapolis, Minnesota; and Adjunct Professor of Medical Ethics, United Theological Seminary, New Brighton, Minnesota. He received his MD from the University of Illinois College of Medicine. He is chair of the Ethics and Humanities Subcommittee of the American Academy of Neurology. His research interests in bioethics include termination of treatment, brain death, persistent vegetative state, and institutional ethics committees.
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 education from the University of Minnesota. She was a Visiting Scholar at the Hastings Center, and held a Fellowship with the Kellogg National Leadership Program.

Rosalie Kane, DSW, is Professor in the Division of Health Services Research and Policy, School of Public Health; Adjunct Professor in the School of Social Work, College of Human Ecology; and Director of the National Long-Term Care Resource Center, University of Minnesota. She is also a Senior Fellow of the Brookdale Foundation. She earned her MA degree from Simmons College School of Social Work and her DSW from the University of Utah. Her research interests in bioethics include the exploration of appropriate autonomy for nursing home residents and home care clients; values assessment and application of client 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. She is the author of numerous books, journal articles, and book chapters.

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 (CUHCC); 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 of Medicine at Keio University Medical School in Tokyo, Japan.

Edward Ratner, MD, is Assistant Professor in the Department of Medicine, University of Minnesota. 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 John Song, Dr. Ratner recently collaborated on a paper, “Ethics of Dying at Home” published in *Home Health Care Management*; and together they are collaborating with Dianne Bartels on a project “End of Life Care for the Homeless and the Homebound.” Dr. Ratner is currently 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 work in bioethics is on the use of empirical data to help focus ethical debate and on issues in end-of-life care. She is co-editor of *Handbook on Ethical Issues in Aging* (Greenwald Press, 1999).
Center Associates

Miriam Cameron, RN, PhD, MS, MA, is Faculty Member, Center for Spirituality and Healing, University of Minnesota. She received her MS in nursing, MA in philosophy/bioethics, and PhD in nursing/bioethics from the University of Minnesota. She did postdoctoral work in nursing and bioethics at the University of Minnesota, Georgetown University, University of Wisconsin, University of Illinois, and the Midwest Bioethics Center. The National Institute of Nursing Research (NIH) and other agencies have funded her ethics research in the US and Korea. She is the author of numerous articles, book chapters, and books. Currently, she is working on ethical issues involving end of life care and cultural diversity and the relationship between ethics, spirituality, and healing.

Bonnie LeRoy, MS, is Associate Professor, Department of Genetics, Cell Biology and Development; and the Institute of Human Genetics, University of Minnesota. She received her Masters degree in Genetic Counseling from Sarah Lawrence College in New York and she directs the University of Minnesota’s Graduate Program in Genetic Counseling. Together with Dianne Bartels, she teaches a course on “Ethical Issues in Genetic Counseling.” She has collaborated with Dianne Bartels and Patricia McCarthy Veach on the development of a Genetic Counseling Skills textbook and on the project, “Genetics in Primary Health Care: Addressing Professional and Ethical Challenges,” funded by the Josiah Macy, Jr. Foundation.

Anna Mastroianni, JD, MPH, is Assistant Professor at the University of Washington School of Law; University of Washington Institute for Public Health Genetics; Department of Health Services, School of Public Health and Community Medicine; and Department of Medical History and Ethics, School of Medicine, University of Washington. She received her JD from the University of Pennsylvania Law School and her Masters in Public Health from the University of Washington. She has worked in a number of legal and governmental policy positions in Washington, DC, including Associate Director of the White House Advisory Committee on Human Radiation Experiments and as a Study Director of the Institute of Medicine. She has been nationally recognized for her contributions to health policy, law and bioethics by the American Association for the Advancement of Science. Her publications include four books and numerous articles concerning biomedical research and health policy. Ms. Mastroianni currently is working with Jeffrey Kahn on curricula development in ethics and public health.

Patricia McCarthy Veach, PhD, LP, is Professor of Educational Psychology at the University of Minnesota. She is a member of the Distinguished Academy of Teachers at the University of Minnesota. She earned her MA and her PhD in Counselling Psychology from Ohio State University. Her research interests in bioethics include genetic counseling service provision, and ethical and psychosocial aspects of genetic counseling and genetic counseling supervision and training issues. Her most recent publications include a co-authored book, Facilitating the Genetic Counseling Process: A Practice Manual (Springer Verlag, 2003) and a co-edited special section of the Journal of Genetic Counseling.

Post-Doctoral Fellows

Andrea Nicki, PhD, 2002-03 Post-Doctoral Fellow in the Center for Bioethics, received her PhD in Philosophy from Queens University, Ontario, Canada. Her research includes narrative ethics, women's health, and mental health ethics.

N. Yasemin Oguz, MD, PhD, 2001-02 Post-Doctoral Fellow in the Center for Bioethics, received her MD and her PhD from Ankara University Faculty of Medicine, Ankara, Turkey. Professor Oguz returned to her faculty position at Ankara University in July 2002.

Visiting Faculty

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.”

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 is working with Professor Beth Virnig on a grant submission to NIH to support his research, as well as on a book and several manuscripts.

Carol Tauer, PhD, Professor Emerita of Philosophy, College of St. Catherine, St. Paul, MN. Professor Tauer's research focus is on the ethics of human embryo research, reproductive decisions, and allocation of medical resources.
Research

The Center continues to conduct both conceptual and empirical research to provide scholars and the public with the information and the understanding to confront ethical issues involved in the technological advances in biomedical research, health care and biotechnology. The following is an overview of our research efforts in 2002.

Featured Projects

African Genealogy & Genetics: Looking Back to Move Forward

The Center for Bioethics and the Powderhorn/Phillips Cultural Wellness Center, Minneapolis, MN, collaboratively sponsored a two-day conference “African Genealogy & Genetics: Looking Back to Move Forward” in June 2002 on the University of Minnesota campus. The conference brought together for the first time a gathering of national African American scholars, community members, and religious leaders, in a dialogue on the importance and implications of using technologies and genealogical methods to reconstruct African identity.

Conference objectives focused on:

- understanding the major means of reconstructing African American family lineages
- describing the opportunities and challenges each method brings with it
- recognizing and considering the impact of having genealogical information for individuals, families, and community members
- creating a dialogue with African American scholars and community leaders about the present and future challenges related to genealogical research.

A notable feature of this conference was that high school students from disadvantaged minority neighborhoods presented academic papers in the style of a poster presentation to the gathered community. There was excellent attendance for this event, which was a singular opportunity for these students to present and be heard at a University campus.

Transcripts from the conference have been assembled as a website at www.med.umn.edu/cme/afrgen/africangeneology.html. Steven Miles, MD, is working on publishing a portion of the conference proceedings in a special edition for the Cambridge Quarterly of Health Care Ethics.

The Center for Bioethics gratefully acknowledges the support of the partners and funders for this conference:

- Allina Foundation; Community Action of Minneapolis; The Greenwall Foundation; Insight News; McFarlane Media Interest, Inc.; The Minneapolis Foundation; NIH, National Human Genome Research Institute; and University of Minnesota – Office of Continuing Medical Education, Roy Wilkins Center for Human Relations and Social Justice, Hubert H. Humphrey Institute of Public Affairs, and Medical School Office of Minority Affairs.

Nurses: Research Integrity in Clinical Trials

Joan Liaschenko, RN, PhD, and co-investigators, Debra DeBruin, PhD, and Anastasia Fisher, RN, DNSc, Public Health Institute, Berkeley, California, received a grant from the National Institute of Nursing Research (NINR), NIH to study the ethical issues encountered by nurses working in clinical trials.

Research ethics is, appropriately, a national priority. However in discussions of clinical trials, research ethics focuses nearly exclusively on the perspective of principal investigators. Yet, nurses are key in implementing clinical trials, since they perform much of the day-to-day work that constitute the actual clinical trial. Clinical trial nurses bear responsibility for recruiting participants, obtaining informed consent, monitoring participant responses, charting data, and serving as liaison with study monitors, multi-disciplinary teams, multiple sites, and sponsoring agencies. Staff nurses often administer interventions in trials, thereby adding a layer of complexity to the practice. Given their responsibility for clinical trials, it is stunning that so little is known about how this work is actually done and the ethical issues that clinical trial nurses encounter in this work. This research 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.

The study will use focus group interviews of nurses working in clinical trials involving four disease groups: addictions/mental health, cancer, cardiovascular disease, and neurological disease. The research will be conducted at two sites, Minneapolis and the San Francisco Bay Area. This data will serve as a basis for future research, with two long-term goals for the research program. The first will be to evaluate the adequacy of existing policy and guidance for research involving human participants, which has been developed without an understanding of the concerns confronting nurses in their work in clinical trials. The second will be to reconsider the dominant understanding of the ethics of research, which conceives of moral decision-making as the application of abstract, impartial rules and tends to ignore the ethical importance of context, such as the institutional factors we propose to investigate.

Additional New Funding in 2002

The Center for Bioethics was awarded a three-year leadership grant from the Starr Foundation to support the development of a Bioethics Resource Center and to create and disseminate educational materials on current issues in bioethics (see page 18 for a full description).

Raymond deVries, PhD, and his colleagues were awarded an NIH grant for a four-year project on “The Ethical Problems of Deep Brain Stimulation (DBS).”
Barbara Elliott, PhD, was awarded grants from the National Institute on Aging of NIH, for a project on “Values of Families in Guiding End-of-Life Care;” St. Louis County Public Health Department for a “Teen Life Center Resiliency Project;” Duluth Superior Area Community Foundation for a project on “Health Needs of Adolescents;” and the Minnesota Department of Public Health, the Ordean Foundation, and the Generations Health Care Initiatives for a Teen Life Health Service Center.

Jeffrey Kahn, PhD, MPH, was awarded a grant by the Greenwall Foundation for a project entitled “Towards Guidelines For Conflicts of Interest for Centers and Programs in Bioethics.” Kahn will direct the project along with Ruth Faden, PhD, MPH, of Johns Hopkins University, to convene a national meeting of directors of bioethics centers and programs to discuss and create guidelines for dealing with conflicts of interests.

Anna Mastroianni, JD, MPH, has been named a Greenwall Faculty Scholar in Bioethics. Mastroianni is one of three researchers in the US to receive the prestigious award that will support her study of research and policy development as it relates to stem cells, human embryos, and reproductive technologies.

Edward Ratner, MD, was awarded a faculty development grant from the Primary Care Education Committee, University of Minnesota for research on end-of-life care. He was also awarded a Geriatric Academic Career Award by the DHHS Health Resources and Services Administration (HRSA).

John Song, MD, MPH, MAT, Edward Ratner, MD, and Dianne Bartels, PhD, were awarded a grant from the 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;” Dr. Song was also awarded grants from the Community University Partnership in Education and Service Foundation, Edina Realty Foundation, and the Hennepin County Medical Foundation, for a project on “The Franklin Clinic: A Service-based Educational Opportunity.”

Karen-Sue Taussig, PhD, was awarded a University of Minnesota Grant in Aid and a Department of Anthropology Research Grant for a project on “Genetics and its Publics: Crafting Scientific and Medical Literacies in the New Age of Biotechnology.”

Ongoing Research

“Ethnicity, Citizenship, Family: Identity After the Human Genome Project”

In its second year, this NIH funded project brought a team of researchers, headed by Principal Investigator Carl Elliott, to meetings in Minneapolis and Halifax, Nova Scotia to examine ways in which new methods of tracing genealogies through genetic markers might alter shared understandings of ethnic, religious and national identity. The project has created a website with case studies at www.bioethics.umn.edu/genetics_and_identity/index.html. Project members have published articles on this research in the British Medical Journal, Anthropological Quarterly, Hastings Center Report and The Wilson Quarterly. A special journal issue of Culture, Medicine and Psychiatry and Developing World Bioethics will also be devoted to the project.

“Genetics & Disability Insurance: Ethics, Law & Policy”

The Center was awarded a grant from the National Human Genome Research Institute (NIH) 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. The project in its second year has 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 issues raised by genetic testing have been discussed in the context of life and health insurance, the impact this testing will have on disability insurance 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 will culminate in 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.

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

“International Bioethics Education and Career Development Award” with the Department of Sociology, University of Minnesota—funded by the Department of Health and Human Services, Public Health Service.

“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.

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

“An Ethnographic Study of Institutional Review Boards” with Raymond deVries, St. Olaf College—funded by the National Institutes of Health.

“Institutional Review Boards under the Health Insurance Portability and Accountability Act” with the University of Minnesota—funded by the Office of the Vice President for Research, University of Minnesota.

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

“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.

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


**Articles**


Cutler L, Kane R. Environments for Privacy, Safety, and Movement of Persons with Dementia Maximal Privacy + Moderate Barriers = Minimal Intrusion. *Alzheimer’s Care Quarterly* 2002;3(3):50-54.


Cameron J, Kahn JP. Point/Counterpoint: A Prospective Study Should be Performed to Test the Hypothesis That an Increase in Background Radiation to Residents in the Gulf States Will Increase Their Longevity. *Medical Physics* 2002;29(7):1511-1513.


Bioethics Examiner

The Center published four volumes of the Bioethics Examiner in 2002 bringing cutting edge issues in bioethics to more than 8,500 readers worldwide.


Thinking About Genetics in Everyday Life, by Karen-Sue Taussig, PhD; Spring 2002 (Vol. 6, Issue 1).

Autonomy: Cutting the Gordian Knot, by N. Yasemin Oguz, MD, PhD; Spring 2002 (Vol. 6, Issue 1).

Autonomy: Challenges in Genetic Health Care, by Dianne Bartels, RN, MA, PhD; Spring 2002 (Vol. 6, Issue 1).

Does American Bioethics Have A Soul? by Steven Miles, MD; Summer 2002 (Vol. 6, Issue 2).

Why I am Not a Bioethicist, by Raymond DeVries, PhD; Fall 2002 (Vol. 6, Issue 3).

Abstracts


Monographs & Reports


Columns
Kahn JP. “Ethics Matters,” a bi-weekly column on CNN.com.

Do Embryos Need New Protections?
The Business of Medical Research
Research in Kids: Why it’s Risky, Why it’s Important
Studying Organ Sales: Short-Term Profits, Long Term Suffering
Adoption of Frozen Embryos a Loaded Term
Tainted Gifts of Life
Should We Be Able to Choose Our Children?
West Nile Virus: Far Away or Close to Home?
The Pros and Cons of Halting Research
Medicine in Your Junk Mail
Making Organ Donation a Better Deal
The Value of Vaccination
New Ways to Play with Your Food
Implanting Ideas to Store Medical History
Building Public Trust in Research
What’s at Stake in the ‘Cloning Wars’?
No Litmus Tests?
The New Personal Code
Choosing Our Children’s Future or Choosing Our Future Children?
The Questionable Future of Unregulated Reproduction
Prisoners and Transplants
Dying to Donate
Cloning Pigs for Parts

Editorial Board Memberships and Peer Reviewers
Center faculty served as editors, advisors, editorial review board members, and peer reviewers for leading funders, professional journals and academic presses including:
Agency for Health Care Policy Research
American Ethnologist
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
Brazilian Journal of Nursing
Cambridge Quarterly of Health Care Ethics
Cambridge University Press
Canadian Journal of Nursing Research
Christian Scholar’s Review
Community Genetics
Configurations
Cornell University Press
The Counseling Psychologist
Culture, Medicine & Psychiatry
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
Health Affairs
Health and Social Work
Health Care Financing Review
Health Services Research
IRB: Ethics & Human Research
Journal of Aging and Identity
Journal of Andrology
Journal of the American College of Dentists
Journal of the American Dental Association
Journal of American Geriatrics Society
Journal of American History
Journal of the American Medical Association
Journal of Cancer Education
Journal of Clinical Ethics
Journal of Comparative Family Systems
Journal of Counseling Psychologist
Journal of Dental Education
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 Gerontology
Journal of Health Politics, Policy and Law
Journal of Law, Medicine and Ethics
Journal of Moral Education
Journal of Philosophy, Science & Law
Journal of Policy, Politics, & Law
Journal of Urban Health: Bulletin of the New York Academy of Medicine
Journal of Women’s Health and Law
Kennedy Institute of Ethics Journal
Lancet
Law, Medicine & Health Care
MacMillan Sciences Library: Computer Sciences Vol. 4
Medical Anthropology
Medical Anthropology Quarterly
Medical Care
Medical Research Council of Canada
Milbank Quarterly
MIT Press Basic Bioethics Series
National Academy of Sciences, Institute of Medicine
National Human Genome Research Institute (NIH)
National Research Council
New England Journal of Medicine
New Zealand Journal of Bioethics
New York University Press
North American Primary Care Research Group
Nursing Ethics
Nursing Inquiry
Nursing Philosophy
Online Journal of Health Ethics
Oxford University Press
Perspectives in Biology and Medicine
Philosophy, Psychiatry and Psychology
Qualitative Sociology
Research Council of Canada
Scholarly Inquiry for Nursing Practice
Science
Science and Engineering Ethics
Social Problems
Social Science and Medicine
Social Services Review
Sociology of Health and Illness
Teaching and Learning in Medicine
Theoretical Medicine
Women and Health
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 2002.

**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. 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,” “Enhancement Technologies and Human Identity.”

**Nursing**

The University of Minnesota School of Nursing has a long history of including ethics education across all three levels of the curriculum: baccalaureate, masters, and doctorate. Professor Joan Liaschenko is currently responsible for teaching the required course at the masters’ level, “Moral and Ethical Problems in Nursing.” This course is designed to help students increase their knowledge of the domains of ethical experience and various approaches to ethical issues in practice, and to help students articulate the ethical issues they experience in practice and to justify the reasons for their taking one course of action over another.

**Public Health** *(courses are also offered on-line)*

“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 Debra 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. Professor’s 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.

**Medical School**

“Physician & 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 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 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 a 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.
“This September, I return to Lawrence University in Appleton, Wisconsin as a senior in philosophy. Advance Directives is the topic I chose to do an independent study on this year. Educational resources and materials that were provided to me, and discussion with faculty and staff about the need for and potential problems of health care directives will be extremely valuable when preparing my thesis. This internship has encouraged me to broaden my views of bioethics.”

- Jason Hanna, Student Intern, (Lawrence University) Summer 2002

College of Biological Sciences

“Ethics Component: Research Experiences for Undergraduates in Molecular Biology”

This is the fourth year the Center for Bioethics has collaborated with the College of Biological Sciences to provide a four-week course on ethics in research for undergraduates enrolled in the Life Sciences Summer Undergraduate Research Program in College of Biological Sciences. 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 the Department of Philosophy, School of Public Health, and the Law School, including the Joint Degree Program in Law, Health and 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 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 for students in philosophy, public health (health services research and policy), nursing, social work, and dentistry. 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 a 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.

Health Law

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 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, patients’ rights, and the division of regulatory responsibility between state and federal authorities.
**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:**

- CVM 6012: Integrative Medicine
- Dent 5412: Professional Problem Solving
- Dent 6416: Professional Problem Solving
- GCD 8073: Lectures in Psychosocial Genetic Counseling and Ethics Considerations in Genetic Medicine
- GCD 8912: Genetic Counseling in Practice
- GCD 8914: Ethical and Legal Issues in Genetic Counseling
- GCD 8920: First/Second Year Genetic Counseling Special Topics Seminar
- InMd 6050: Physician and Society I
- InMd 6051: Physician and Society II
- Law 6605: Health Law
- Law 6875: JDP Proseminar Law, Health & the Life Sciences
- Med 7598: Biomedical Ethics
- Med 7599: Bioethics Theory
- Nurs 4407/HSEM 3070: Seeking Solutions in Global Health Issues
- Nurs 8140: Moral and Ethical Positions in Nursing
- Phil 8320: Seminar in Medical Ethics
- PubH 5741: Ethics in Public Health: Professional Practice and Policy
- PubH 5742: Ethics in Public Health: Research and Policy

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

- Biomedical Engineering Seminar
- Carlson School of Management
  - Health Administration
  - Issues of Justice In Health Care Systems
  - Drug Industry and Health Administration
  - International Financial Organizations and Health Care Systems
- Center on Aging
- Center for Victims of Torture
- Chemistry Seminar
- CHIP Series on International Health Care
- College of Education and Human Development
- Consortium on Law and Values in Health, Environment & the Life Sciences Seminar Series
- Faegre & Benson Lecture Series
- Fairview University Medical Center Social Work Inservice Program
- Freshman Biology Colloquium – Genetic Counseling Career Planning
- Human Genetics Course Year 1, Psychosocial Issues in Genetic Counseling
- Graduate Women in Science Lecture Series
- Medicine House Staff Conference
- International Human Rights Conference
- Joint Degree Program in Law, Health & the Life Sciences
- Minnesota Area Geriatric Education Center (MAGEC) Lecture Series
- Mayo Clinic Family Practice Residency Program
- Medical School
  - Clinical Training (CUHCC)
  - Geriatric Seminar on Functional Assessment
  - Graduate Medical Education Core Conference
  - Health Advocacy
  - Internal Medicine – Noon Conference
  - Issues in the ICU
  - Medical Ethics and End of Life Care, Noon conference
  - Medicine Grand Rounds
  - "On Doctoring" Series
  - Physician and Society
  - Psychiatry Residents Presentation
  - Surgery Grand Rounds
- Women's Health and Human Rights: International Perspectives
- Responsible Conduct of Research
- School of Nursing
  - Nursing Graduate Class
  - Nurse Practitioner Program
  - Senior Nursing Students Program on “Final Touches: The Nurse’s Role in the Care of the Dying”
- Summer Scholars Program – Morris campus
- Undergraduate Ethics Honors Class
- VA Psychology Grand Rounds
- Vital Aging Initiative
The Center 2002 lecture series on current topics in bioethics, included:

“Naming Genes: Patenting and the Legal Construction of Authority Over Human Genetic Material” by Jonathan Kahn, JD, PhD, Research Associate, Consortium on Law and Values in Health, Environment & the Life Sciences; Joint Degree Program in Law, Health & the Life Sciences; Center for Bioethics; Adjunct Associate Professor of Law, University of Minnesota.

“International Policies on Stem Cell Research” by Josie Johnston, Research Associate, Center for Bioethics, University of Minnesota.

“Who Decides? The Compositions and Characteristics of Institutional Review Boards” by Raymond deVries, PhD, Visiting Faculty, Center for Bioethics, University of Minnesota; Associate Professor, St. Olaf College and Carl Forsberg, Science Department, Breck School Research Program.

“Abortion and End of Life Care in the Hippocratic-era Medicine” by Steven Miles, MD, Professor of Medicine and Geriatrics, Center for Bioethics, University of Minnesota.

“The Value of Life According to Islam” by N. Yasemin Oguz, MD, PhD, Post-Doctoral Fellow, Center for Bioethics, University of Minnesota.

“Health Care in Nazi Germany: Meanings and Morality” by Andrea Mineau, PhD, Department of Religious Studies and Ethics, University of Quebec, Rimouski.

“Do Patients Have a Clue? A Look at How to Improve Patients’ Health Care Decisions” by Peter Ubel, MD, Director, Program for Improving Health Care Decisions, Ann Arbor VAMC and University of Michigan.

“Stem Cell and Cloning Research: Public Policy and Private Enterprise” by Carol Tauer, PhD, Visiting Faculty, Center for Bioethics, University of Minnesota.

“Moral Worry as a Dimension of Personal Agency” by Jerome Kroll, MD, Department of Psychiatry, University of Minnesota Medical School.

Co-sponsored seminars

Eleventh Annual Max and Rose Sadoff Memorial Symposium on Pharmacy, Law and Ethics

“Of War and Values: What is a Professional to Do?” by Linda Emanuel, MD, PhD, Director, Buehler Center on Aging; Professor, Health Industry Management, Northwestern University.

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

“Balancing Public Health and Patients’ Rights: The Threat of Bioterrorism” by Wendy Mariner, PhD, with commentators Jan Malcolm and Debra DeBruin, PhD.


“Restrictions on Privacy, Autonomy & Liberty: Lessons from Infectious Disease Control” by Ronald Bayer, PhD, with commentators Harry F. Hull, MD, and Steven Miles, MD.

Lunch Series on the Societal Implications of the Life Sciences


“Genotoxicity: Ethical Issues at the Intersection of Genetics and the Toxicological Sciences” by Richard R. Sharp, PhD.

“From Laboratory to Clinic: Issues in the Oversight of Innovative Reproductive Technologies” by Andrea Bonnicksen, PhD.

“Human Molecular Genetics and the Subject of Race: Contrasting Theory and Rhetoric with Practical Applications in Law and Medicine” by Troy Duster, PhD.

Elder Learning Institute Bioethics Series

Center faculty taught an 8-week lecture series addressing contemporary issues in bioethics.
Outreach

The Center for Bioethics is a resource for the University community, health care professionals, students, policy makers, researchers and the public. The following reflects our outreach activities in 2002.

Resource Center Development

The Center for Bioethics received a three-year leadership grant from the Starr Foundation. With this support, the Center for Bioethics increased efforts to develop educational materials and resources on bioethics and on new and emerging technologies in health care and biomedical research. In keeping with the Center’s mission to provide education in bioethics for members of the University community as well as members of the general public, new staff were hired and an office was created to promote accessibility for those seeking resource materials.

Directed by Dianne Bartels, the Resource Center staff developed and conducted a needs assessment survey of a broad range of health care professionals, faculty, staff, and students to assess the kinds of ethics resources they would find most helpful. We also asked how they would like these resources made available to them. In response to these surveys and other requests, we developed a resource section on the Center’s website. We produced a new publication entitled, “Human Stem Cells: An Ethical Overview,” tailored for those who desire a basic understanding of the current ethical issues involved in stem cell research. This publication is available on line or can be mailed upon request. With enhanced website and email capability, Center resources are now more accessible to students, professionals, and to the general community.

Resource Center staff also supported the efforts of the Minnesota Network of Healthcare Ethics Committees (MNHEC) to host workshops and to generate and distribute educational materials to its members throughout Minnesota and Wisconsin.

The Minnesota Network of Healthcare Ethics Committees (MNHEC)

Administered by the Center for Bioethics, the Minnesota Network of Healthcare Ethics Committees (MNHEC) entered its second year with memberships from across Minnesota and Wisconsin representing acute care facilities, state medical facilities, board and care homes, long-term care facilities, a state guardianship agency, and an ethics center. MNHEC continued its efforts to provide mechanisms for education and interaction among members of these facilities.

Network staff and members worked closely with Center staff to develop programs and policies. In 2002, MNHEC hosted a number of conferences at four sites in Minnesota to provide basic information about ethics committee development. These conferences were titled, “Ethical Challenges in Patient Care,” “On Starting and Maintaining Ethics Committees,” and “Ethics Committees: The Consultation Process.” Following each of these conferences, packets of resource materials, offering basic information as well as more advanced organizational ethics content, were made available to network members and to the general public upon request.

MNHEC continued to host a listserv on which members exchanged information about the daily challenges they face in their health care facilities. Members learned and found support from these exchanges as they discussed different approaches and shared strategies that were successful in meeting ethical challenges. These discussions addressed topics including patient rights, patient and family decision-making, family member involvement, ethics committee mission, access to health care, and end of life treatment decisions.

The Center participates in a wide variety of efforts at the local, state, and national levels by sponsoring conferences and lectures, in 2002.

African Genealogy and Genetics: Looking Back to Move Forward

The Center for Bioethics conducted a two-day meeting in cooperation with the Powderhorn/Phillips Cultural Wellness Center, Minneapolis, MN. The conference was covered on local television, on the front page of the Minneapolis Star Tribune and in the local minority press. See page 7 in this publication for full details.

Exploring Ethics and Public Health: An Intensive Workshop

The Center for Bioethics and The Hastings Center hosted a summer intensive workshop on ethics and public health. The workshop co-sponsored by the Association of Schools of Public Health, and the University of Minnesota’s School of Public Health, Academic Health Center, and Department of Continuing Medical Education, provided intensive study and discussion of approaches and frameworks for a range of ethical issues in public health. Topics included responses to bioterrorism; infectious disease control; genetics—screening programs and individual testing; public health research and practice—domestic and international settings; and teaching ethics and public health.

“What’s Bioethics?”

The Center presented mini-sessions on “What’s Bioethics?” at the University-sponsored event for the national “Take Our Daughters to Work Day.” Students were invited to visit the Center and discuss questions about issues in health care and science. The Center also hosted a similar session in the Academic Health Center’s exhibit at the Minnesota State Fair.
Co-sponsored Conferences in 2002

“The Law and Ethics of Public Health Responses to Bioterrorism”
symposium co-sponsored with the University of Minnesota Consortium
on Law, Health & the Life Sciences.

“Pharmacogenomics the Legal, Ethical & Clinical Challenges”
conference co-sponsored with the Consortium on Law and Values in
Health, Environment & the Life Sciences; Joint Degree Program in Law,
Health & the Life Sciences; College of Pharmacy; MD/PhD Program;
Biomedical Genomics Center; and the Department of Pharmacology.

“The Painful Truth” a community forum on the under treatment of pain
presented by Ira Byock, MD, past president of the American Academy
of Hospice and Palliative Medicine, co-sponsored with the Minnesota Hospice
Association; AARP; Alzheimer’s Association; American Cancer Society; Care
Providers of Minnesota; Children’s Home and Hospice; HealthEast Hospice;
Medtronic, Inc.; and Methodist Hospital Hospice; Metropolitan Area
Agency on Aging; Minnesota AIDS Project; Minnesota Health & Housing
Alliance; Minnesota Partnership to Improve End of Life Care; Minnesota
Senior Federation; Purdue Pharma; and the St. Paul Foundation.

“Medical Anthropology for the 21st Century: Medicine, Culture, Power”
conference, co-sponsored with the University of Minnesota Department’s
of Anthropology; Office of the Vice President and Provost; Institute for
Global Studies; Humanities Institute; College of Liberal Arts; Consortium
on Law and Values in Health, Environment & the Life Sciences; McKnight
Arts; and the Humanities Endowment.

“Women’s Health and Human Rights: International Perspectives”
conference, co-sponsored with the University of Minnesota Medical
School, Academic Health Center, College of Liberal Arts, Minnesota
International Health Volunteers, and Physicians for Social Responsibility.

Faculty Service on University of Minnesota
Committees and Boards

Advisory Committee for Research and Grants Management Education
Advisory Committee on Institutional Priorities to the Civic Engagement
Task Force
Biomedical Research Integrity Advisory Committee
Blood Borne Disease Policy Committee, Medical School
Center for Holocaust and Genocide Studies Advisory Board
Clinical Research Panel, Graduate School
Community University Partnership in Education and Service Board
Faculty Education Advisory Committee on Responsible Conduct of Research
Genetic Counseling Graduate Program Admissions Committee
Genetics/Genomics Integration Work Group, Medical School
Graduate Program in Genetic Counseling Selection Committee
Graduate School Clinical Research Panel
Human Subjects Education Committee
Joint Degree Program in Law, Health & the Life Sciences, Law School,
Governing Committee
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
Regulatory Affairs Certificate Program Advisory Board
Research Ethics Advisory Committee
School of Dentistry, Promotion and Tenure 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
University of Minnesota, Duluth (UMD); Vision Committee; Research
Advisory Committee, University Senate Committee on Committees;
Whiteside Research Committee; Space Committee; Commission on Women; Center for Rural Mental Health; Campus Assembly Standing Committee
Faculty service on State and National Boards and Committee Memberships

Advanced Cell Technology Ethics Advisory Board
American Academy of Home Care Physicians
American Anthropological Association Meetings Panel
American Association of Law Schools Section on Intellectual Property
American Association for Dental Research Awards Committee
American Board of Genetic Counseling
American College of Epidemiology Ethics Standards and Practice Committee
American Educational Research Association Awards Committee
American Medical Association – Genetic Education Advisory Group
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 Human Genetics Consumers Issues Committee
American Society of Law, Medicine and Ethics Board of Directors
Association for Moral Education Awards Committee
Association of American Medical Colleges Task Force on Financial Conflicts of Interest
Choice In Dying Board of Directors
Cornell Computer Law & Policy Institute Advisory Board
Death with Dignity Education Center Board of Directors
Episcopal Diocese of Minnesota Examining Chaplain for Ethics and Moral Theology
Health Alliance International Board of Directors
Hospice of the Twin Cities Professional Advisory Council
International Health Care Worker Safety Center Commission on Legal, Ethical, and Medical Issues of Transmission of Bloodborne Pathogens, University of Virginia
LifeSource (OPO) Medical Ethics Advisory Committee
Long Island Breast Cancer Study Project (LIBCSP), NCI, Oversight Committee for the Geographic Information System (GIS)
Miller-Dwan Medical Center Ethics Committee
Minneapolis Urban Coalition Health Advisory Board
Minnesota Asian American Health Coalition Board
Minnesota Association for Human Genetics Board of Directors
Minnesota Center for Victims of Torture Institutional Review Board
Minnesota Commission on End of Life Care
Minnesota Department of Health and Human Services – Transplant Advisory Committee
Minnesota Medical Directors Association Board
National Children's Study Ethics Working Group
National Hemlock Foundation Board of Directors
NIH Data and Safety Monitoring Board of the Sudden Cardiac Death in Heart Failure Trial
NIH Study Section, International Bioethics Education and Career Development, Fogarty International Center
NIH Study Section, Environmental Justice, National Institute for Environmental Health Sciences
NIH Special Emphasis Panel on Informed Consent in Research
National Marrow Donor Program Board of Directors
North Memorial Hospital Biomedical Ethics Committee
Oakwood Foundation Board of Directors
Page Foundation Mentor
Phillips/Powderhorn Wellness Center Grants Advisory Board
Professions Education Research Quarterly Advisory Board
Professional Ethics in Dentistry Network Committee
Robert Wood Johnson Foundation National Advisory Committee on End-of-Life Care
St. Luke's Hospital of Duluth Ethics Committee
St. Mary's Medical Center Ethics Committee
United Network of Organ Sharing (UNOS) Ethics Committee
Walker Care Corporation Board
We presented our work and delivered lectures in a variety of public settings.

**Local and Regional Presentations**

3M Corporation  
Seminar on Biotechnology  
St. Paul, MN

ING Life Insurance  
18th Annual Rose Seminar  
St. Paul, MN

Allina Social Workers  
Annual State Meeting  
Minneapolis, MN

Fairview University Medical Center  
Social Workers Conference  
Minneapolis, MN

First Lutheran Church  
St. Peter, MN

Hennepin Medical Society  
Physicians Association Meeting  
Minneapolis, MN

Jewish Community  
Center of St. Paul  
St. Paul, MN

LifeSource Regional Conference  
Minneapolis, MN

Medical Alley Clinical Studies Conference  
Minneapolis, MN

Metro Minnesota Chapter of The Oncology Nursing Society  
Minneapolis, MN

Minnesota Hospice Association Community Forum  
St. Paul, MN

Minnesota Hospital and Healthcare Partnership 10th Annual Trustee Conference  
Plymouth, MN

Minnesota Nurses Association Conference  
St. Paul, MN

National Council of Women Judges Conference on Genome Justice  
Minneapolis, MN

Rice Memorial Hospital Ethics Committee  
Willmar, MN

St. Mary’s Clinic Hospice Workshop  
Duluth, MN

Hubert H. Humphrey Institute of Public Affairs  
Tuberculosis and World Health Conference  
Minneapolis, MN

University of Minnesota International Human Rights Conference  
Minneapolis, MN

Veterans for Peace  
Afghan Refugees in Iran  
Minneapolis, MN

Women’s Club of Minneapolis Healthcare Reform  
Minneapolis, MN

Woodlyn Health Care Center Ethics Consultation  
Woodlyn, MN

**National and International Presentations**

5th International Bioethics Retreat  
Almagro, SPAIN

5th International Congress on Lung Transplantation  
Paris, FRANCE

12th Annual Conference on Computers, Freedom and Privacy  
San Francisco, CA

27th Congress of the International Society of Blood Transfusion  
Vancouver, CANADA

30th Telecommunications Policy and Research Conference  
Alexandria, VA

III World Congress of Bioethics  
San Francisco, CA

Academy of Health Services Research and Health Policy (AHSRHP) Annual Meeting  
Washington, DC

AIDS & Ethics: First International Conference on Protections for Hospitalized Persons with AIDS  
San Francisco, CA

American Academy of Home Care Physicians (AAHCP) Annual Meeting  
Washington, DC

American Anthropological Association Annual Meeting  
New Orleans, LA

American Association for Cancer Education Annual Meeting  
Toronto, CANADA

American Dental Education Association Annual Meeting  
San Diego, CA

American Diabetes Association 62nd Scientific Sessions  
San Francisco, CA

American Educational Research Association Annual Meeting  
New Orleans, LA

American Medical Directors Association Annual Meeting  
San Diego, CA

American Nurses’ Association 130th Annual Meeting  
Philadelphia, PA

American Nurses’ Association Second National Institute on Nursing Ethics  
Chicago, IL

American Philosophical Association Midwest Meeting  
Atlanta, GA

American Public Health Association 130th Annual Meeting  
Washington, DC

American Radiation Safety Conference and Exposition  
Tampa, FL

American Society of Bioethics and the Humanities 5th Annual Meeting  
Baltimore, MD

American Society of Law & Medicine Fall 2002 Conference  
Boston, MA

American Society of Law, Medicine & Ethics Annual Meeting  
Cambridge, MA

American Society for Suicide Prevention National Task Force on Preventing Physician Suicides  
Washington, DC

American Sociological Association Annual Meeting  
Chicago, IL

American Stroke Association 27th International Stroke Conference  
San Antonio, TX

American Transplant Congress Transplant 2002  
Washington, DC

Annual Conference of the Association for the Study of Law, Culture & the Humanities  
Philadelphia, PA

Annual Conference of the Society for the Social Studies of Science  
Milwaukee, WI

Aspen Allergy Conference  
Aspen, CO

Association of American Universities Council on Federal Relations Annual Retreat  
Tucson, AZ

Association of Internet Researchers 3rd Annual Meeting  
Maastricht, NETHERLANDS

Association of the Bar of the City of New York Annual Meeting  
New York, NY

Association for Baha’I Studies Conference  
Toronto, CANADA

Association for Practical and Professional Ethics Annual Meeting  
Cincinnati, OH

Bioethics and the Health Professions Conference  
Lake Louise, CANADA

Bioethics Institute 2002 Annual Meeting  
Madison, WI

Boston College Law School Annual Meeting  
Newton, MA

Boston College Law School Annual Meeting  
Boston, MA

Boston University School of Public Health  
Boston, MA
Brandeis University
Graduate Program in
Genetic Counseling
Boston, MA

Brody School of Medicine
Department of Medical Humanities
East Carolina University
Greenville, NC

Brook General Hospital
Grand Rounds
Fort Lauderdale, FL

Bulgarian Medical Academy
Institute of Social Medicine
International Conference on
Bioethics and Biolaw
Sofia, BULGARIA

The Cambridge Hospital
Fraiman Lecture on Termination
of Treatment
Cambridge, MA

Center for Ethics and Caring
Public Forum
Sioux Valley Hospital
Sioux Falls, SD

Central Florida Bioethics
Consortium
Annual Meeting
Fort Lauderdale, FL

Children's Hospital
Ethics Committee Meeting
Boston, MA

Collaborative Family
Healthcare Association
5th Biennial Conference
Clearwater, FL

Columbia Law School
New York, NY

Cornell University
Science and Technology Studies
Ithaca, NY

East-West Conference on Bioethics
Pecs, HUNGARY

ELSI Genetic Variation RFA
Consortium
Chevy Chase, MD

Engineering Food,
Engineering People: Ethics
and the Biotech Revolution
Pomona, CA

European Association for the
Study of Science and Technology
Annual Meeting
York, ENGLAND

Faculties Universitaires
Notre-Dame de la Paix
Centre de Recherches
Ingormatique et Droit
Numru, BELGIUM

First International Conference on
Bioethics and Biolaw
Copenhagen, DENMARK

Friends Research Institute
National Conference on the Ethics
of Research with Children
San Francisco, CA

George Washington University
Dean Dinwoody Center for
Intellectual Property Studies
Intellectual Property Workshop
Washington, DC

George Washington University
National Health Policy Forum
Washington, DC

Georgetown University
Kennedy Institute of Ethics
Intensive Bioethics Course
Washington, DC

Georgia Dental Association
Annual Meeting
Amelia Island, FL

Gerontological Society of America
International Conference 2002
Boston, MA

Group Health Association of America
Annual Medical Directors
Conference
Washington, DC

Harvard Medical School
Division of Aging
Boston, MA

Harvard Medical School
Division of Medical Ethics
Boston, MA

Harvard University
Dana-Farber Cancer Institute
Grand Rounds
Boston, MA

HIV Prevention in South
Sudan Conference
CDC, WHO, American Refugee
Committee, International
Rescue Committee
Kampala, UGANDA

The Ian Ramsey Center
Hastings Center Consultation
Windsor Castle, ENGLAND

Institute of Judicial Administration
Appellate Judges Seminar on
Bioethics
New York, NY

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

International Association
on the History of Medicine
Istanbul, TURKEY

International Society for
Quality of Life Research
9th Annual Conference
Orlando, FL

International Sociological
Association
Annual Meeting
Brisbane, AUSTRALIA

International Symposium on
Technology and Society: 2002
Raleigh, NC

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

Johns Hopkins University School
of Medicine–Brin Lecture
Baltimore, MD

Kansas Health Ethics Annual
Conference
Wichita, KS

Kasier Permanente
Intensive Seminar in Bioethics
Costa Mesa, CA

Lawrence University
Program in Biomedical Ethics
Appleton, WI

MacLean Center for Clinical Ethics
International Financial
Organizations & Health Care
Reform
Chicago, IL

Medical College of Wisconsin
Froedert Hospital
Milwaukee, WI

MedTech
Continuing Medical
Education Lecture
Fort Lauderdale, FL

Memorial Sloan-Kettering
Cancer Center
Heritage, Health and
Hope Forum
New York, NY

Middlebury College
Middlebury, VT

National Academy of Science
Institute of Medicine
Washington, DC

National Association of College
and University Attorneys (NACUA)
42nd Annual Conference
Boston, MA

National Cancer Institute
Using SEER-Medicare for
Epidemiologic & Health Service
Research
Bethesda, MD

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

National Judicial College
Symposium on Bioethics
and the Judiciary
Reno, NV

National Kidney Foundation
of Middle Tennessee and
Vanderbilt University
Issues in Transplantation and
Organ Procurement 2002
Nashville, TN

National Patient Safety Foundation
Accountability in Clinical Research:
Balancing Risk and Benefit
Indianapolis, IN

National Society of Genetic
Counselors Annual Meeting
Phoenix, AZ

New York Academy of Medicine
New York, NY

New York Public Library
Celeste Bartos Forum
New York, NY

New York University
School of Law
New York, NY

Office of Research Integrity Meeting
Washington, DC

Office of Research Integrity and
the Cleveland Clinic Foundation
Conference
Cleveland, OH
The Center continues to promote and support public awareness in bioethics in the media. Center faculty responded to inquiries about ethical issues in current events through interviews, articles, and editorials in local and national media.

**Print Media**
- AHC Community News
- AHC News Capsules
- American Medical News
- Arizona Daily Star
- Asahi Shim Bun (Japan) Associated Press
- Birmingham News
- Care Providers Action Newsletter
- Chicago Sun-Times
- Chicago Tribune
- Chronicle of Higher Education
- Christian Science Monitor
- Des Moines Register
- Duluth News Tribune
- El Pais (Madrid)
- Hamline University Press
- Hartford Current
- Hospitalist & Inpatient Management Report
- Journal of Terminal Oncology
- Ma'ariv (Israel)
- Medical Economics Magazine
- Milwaukee Journal-Sentinel
- Minneapolis Star Tribune
- Minnesota Daily
- Minnesota Nursing Accent
- Nature Magazine
- New York Times
- Outside Magazine
- Raleigh News and Observer
- St. Paul Pioneer Press
- Science & Spirit Magazine
- Seattle Post Intelligences
- South Bend Tribune
- Southeast Angle
- Time Magazine
- Today's Health & Wellness Magazine
- Twin Cities' Business Journal
- University of Delaware UpDate
- US News and World Report
- Washington Post
- West Central Tribune
- Winston-Salem Journal

**Radio and Television**
- ABC News Radio
- ABC World News Tonight
- African Satellite Radio
- AMERICAAlive Radio
- CNN – Medical Unit
- FOX TV
- KARE 11 TV
- KFAI Radio
- KGO Radio
- KSTP TV
- Michael Reagan Talkshow
- Minnesota Public Radio
- MSNBC News
- NBC Dateline
- NPR’s All Things Considered
- Radio Health Journal
- RBN Radio Productions’ Ruth Kozlak Show
- Science Times TV
- WCCO Radio
- WCCO TV
- Wired News
- WMNN Radio
- WRKO Radio

**Online Media**
- amednews.com
- CNN.com
- CNNi Live Online Chat
- Reuters.com
- Starbulletin.com
- Washingtonpost.com
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- Miriam Cameron, PhD, RN
  Faculty, Center for Spirituality and Healing, University of Minnesota
- John Hammerly, MD
  Medical Director, Allina HealthSpan Home & Hospice
- Bonnie LeRoy, MS
  Director, Genetic Counseling Graduate Program, Institute of Human Genetics, University of Minnesota
- Carl Malmquist, MD
  Professor of Social Psychiatry
  Department of Sociology, University of Minnesota
- Anna Mastroianni, JD, MPH
  Assistant Professor
  School of Law and Institute for Public Health Genetics
- Patricia McCarthy Veach, PhD
  Professor, Educational Psychology
  University of Minnesota
- Mila Aroskar, RN, EdD
  Patricia Crisham, PhD, RN
  Muriel Ryden, PhD, RN
- Anna Mastroianni, JD, MPH
  Assistant Professor
  School of Law and Institute for Public Health Genetics Adjunct Assistant Professor
  School of Public Health and Community Medicine, University of Washington
- Patricia McCarthy Veach, PhD
  Professor, Educational Psychology
  University of Minnesota
- Frank Snowden, PhD
  University of Minnesota
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  Administrative Aide
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