



**STANFORD UNIVERSITY**  
SCHOOL OF MEDICINE  
**Center for Biomedical Ethics**

# **ANNUAL REPORT**

**2001 - 2002**

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<http://scbe.stanford.edu>

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## **I. OVERVIEW**

### **A. The State of the Center: 2001-2002**

Established in 1989 by Thomas A. Raffin, M.D. and Ernlé W.D. Young, Ph.D., the Stanford Center for Biomedical Ethics (SCBE) grew from the shared interests of medical school and campus faculty concerned with ethical issues in the biomedical sciences and clinical medicine. They foresaw the ethical challenges that would be faced by the medical profession and the threats that can undermine the trust of patients and research subjects.

Challenges in biomedical ethics arise from complex, interdependent factors in society: the constant development and deployment of new technologies in biology and medicine; the increased interactions and tensions between medicine and business; the changing economics of health care in the United States and the economic pressures exerted on health care providers and institutions; the way the law in its many guises—case law, regulation, and legislation—is evolving; the advent of new diseases such as HIV/AIDS and the potential resurgence of old diseases like smallpox in the hands of bio-terrorists; and the major demographic shifts occurring in our society, particularly in terms of the aging of America and our increased ethnic, cultural, and religious diversity.

The Stanford Center for Biomedical Ethics continues to play a unique role among ethics centers nationally, because it engages not only in traditional philosophical inquiry, but leads the nation in ground-breaking interdisciplinary research on moral questions arising from the complex relationships among medicine, science and society. Our research draws on and extends the scientific, clinical and educational strengths of Stanford University, and plays a key role in shaping national health policy. We are committed to exploring and promoting trustworthy and compassionate approaches to the practice of medicine in an environment of rapid socioeconomic and technological change.

As we complete our 13<sup>th</sup> year, the Center is positioned as a national leader in critical analysis of emerging trends in biomedicine and their impact on people and society, in the education of medical professionals, and in informed policy-making. Below are recent accomplishments of the past two years.

### **B. Highlights: Recent Contributions and Accomplishments**

- Center researchers formed important new collaborations as co-investigators on grants with researchers at the School of Medicine and other schools on campus to jointly tackle key ethical and policy questions in the areas of stem cells, bioinformatics, tissue engineering and transplantation, genetic testing and medical imaging.
- Center researchers continued to fully support themselves as principal investigators of over 20 active grants, and applied for 10 new grants. Extramural funding provided roughly 70% of total funding. Of the remaining 30%, 20% came from gifts and 10% from University

support. Recent awards include grants from the NIH for research on the genetics of nicotine addiction, for the development of educational curricula for genetics researchers, development of a conference to define the new field of neuroethics, research on promoting effective communication and decision-making for diverse populations, and making educational documentary films on cultural issues in medicine.

- Center researchers participated in teaching over 30 courses on the Stanford campus, in the schools of Medicine, Business, Engineering and Humanities and Sciences, as well as in the Stanford Hospitals and Clinics. The Center contributed significantly to the integration of ethics components in a growing number of courses in the education of medical and doctoral students. These courses covered a broad range of topics, including genetics, medical innovation, neuroethics, epidemiology, bioinformatics, pharmaceutical development, cultural diversity in medicine, and clinical ethics.
- Center researchers provided service and advice to national policy-makers, including the Congressional Black Caucus on end-of-life care, the Lasker Foundation on biomedical and research ethics, the U.S. House of Representatives Science Committee on gene patenting, and the U. S. Dept. of Health and Human Services Secretary's Advisory Committee on Genetic Testing.
- The Center saw the retirement of Dr. Ernlé Young, a founder and longtime leader of the clinical bioethics program. The Center has also nearly completed recruitment of a replacement to lead and expand the hospital's clinical ethics committee, ethics rounds in the intensive care units and consultation to individual patients, families and health care providers.

## II. CENTER STAFF

### A. Center Leadership

**Mildred Cho, Ph.D.**, is Acting Co-Director and a Senior Research Scholar at the Center. Her major areas of interest are the ethical and social issues raised by new technologies such as genetic testing, gene therapy, pharmacogenetics, and gene patents. She also studies how academic-industry ties affect the conduct of biomedical research.

**Thomas A. Raffin, M.D.**, is Co-Director and the Colleen and Robert Haas Professor of Medicine and Bioethics and Chief of the Division of Pulmonary and Critical Care Medicine. In addition to biomedical ethics - withholding and withdrawing life support, medical decision-making in the context of managed care and HMOs, ethics of neurosciences, and ethical issues in human genetics - Dr. Raffin's key areas of academic interest include biology of acute lung injury, pulmonary fibrosis, and lymphangioliomyomatosis.

**Henry Greely, J.D.**, Chair of SCBE's Steering Committee, is Professor of Law and Professor, by courtesy, of Genetics at Stanford University. Specializing in health law and policy, Greely has

written on cloning, the implications of genetics for the health care system, health care insurance and financing and the stem cell debate.

## **B. Principal Researchers**

**LaVera Crawley, M.D.** is a Lecturer in Medicine with research interests in health disparities in palliative care for African-Americans, as well as race/ethnicity and trust in research and health care. In addition, Dr. Crawley also serves as Executive Director of the “Initiative to Improve Palliative and End-of-Life Care in the African American Community,” a national interdisciplinary working group of African American scholars and professionals.

**Margaret Eaton, J.D., Pharm.D.,** Senior Research Scholar, focuses on the ethical issues in the research, development and marketing of biomedical and genomics products. She is currently Chair of the hospital Ethics Committee and teaches a medical law course in the medical school. Dr. Eaton recently developed a business school course and edited a book on the ethics of the pharmaceutical and biotech industries.

**Linda F. Hogle, Ph.D., M.B.A.,** Senior Research Scholar, studies social and organizational issues in biomedical science, technology and clinical practice. Her focus areas include transplant medicine, tissue engineering, medical device development and ethical issues in market-based health care systems.

**Judy Illes, Ph.D.** is a Senior Research Scholar with a joint appointment in the Department of Medicine and the Department of Radiology. Dr. Illes’ research program is devoted to biomedical ethics in the neurosciences and medical imaging, and to charting the new field of “neuroethics.” Dr. Illes recently played a major role in organizing an international conference co-hosted by Stanford in neuroethics.

**Barbara A. Koenig, Ph.D.,** an anthropologist who studies contemporary biomedicine, is Associate Professor of Medicine. Dr. Koenig is one of a small number of anthropologists whose research contributes to the interdisciplinary field of bioethics. Her work has demonstrated the relevance of empirical investigation to moral inquiry, with a focus on end-of-life care, cultural diversity, technological innovation and genomics.

**Maren Grainger-Monsen, M.D.** is the SCBE Film-maker in residence. Her work is devoted to films on biomedical ethics and culture, faith, and spirituality at the end of life. Her clinical training includes a residency in Emergency Medicine and a fellowship in Palliative Care. Dr. Grainger-Monsen created the award-winning film *The Vanishing Line*. Currently, she is completing a major project on the impact of multiculturalism in medicine.

**Sara L. Tobin, Ph.D., M.S.W.,** Senior Research Scholar in the Program for Genomics, Ethics, and Society, recently completed two nationally acclaimed educational multimedia CD-ROM discs about the genetic revolution in medical care. Her work was sparked by the rapid advances in our knowledge about the human genome.

### **C. Postdoctoral Fellows**

**Sandra Lee, Ph.D.**, Postdoctoral Fellow in the Program for Genomics, Ethics, and Society, is a recipient of a National Research Service Award from the National Human Genome Research Institute. Her research is focused on the ethical and social implications of race in human genetic variation research. Dr. Lee is also a Lecturer in the Department of Cultural and Social Anthropology.

### **D. Associated Faculty**

**Mary Rorty, Ph.D.**, Clinical Associate Professor, has been associated with the Centers for Biomedical Ethics at UVA and at Stanford, and sits on the Lucile Packard Children's Hospital Ethics Committee. She has written on theoretical and practical issues in clinical ethics and bioethics, and is one of several co-authors of the first book ever published on organization ethics in hospitals.

### **E. Emeritus Faculty**

**Ernlé W.D. Young, Ph.D.** is Emeritus Co-Director and Co-Founder of the Center, and Professor of Medicine (Biomedical Ethics). He has been a force in biomedical ethics, chairing the ethics committee at Stanford University Hospital and serving many patients and families confronting moral quandaries.

## **III. RESEARCH**

The Center's three main areas of research are in clinical practice, scientific innovation and health care delivery. The Center currently has grants from both federal and non-federal sources, including National Institutes of Health, Department of Energy, National Science Foundation, The Greenwall Foundation and The Dana Foundation, among others. In addition, Center researchers are participating as co-investigators on over 10 other grants elsewhere on campus that have ethics components.

### **A. Current Funding**

*Beyond Stigma: Interpreting Genetic Differences* (National Institutes of Health). PI: Mildred Cho, Ph.D. 2000-03. Total Funding: \$273,000

*Education in Genetic Ethics* (University of Louisville/ National Institutes of Health). PI: Barbara Koenig, Ph.D. 2002-05. Total Funding: \$410,000

*Effects of Gene Patents on Genetic Testing and Research* (National Institutes of Health). PI: Mildred Cho, Ph.D. 2000-03. Total Funding: \$953,000

*Ethical Challenges in Neuroimaging* (The Greenwall Foundation). PI: Scott Atlas, Ph.D., Co-PI: Judy Illes, Ph.D., Tom Raffin, M.D. 2001-04. Total Funding: \$150,000

*Ethical Dimensions of Neuroscience Research* (Bio-X Interdisciplinary Initiatives Program). Center for Biomedical Ethics – Barbara Koenig, Ph.D., Hank Greely, J.D. 2003-04. Total Funding: \$150,000

*The Ethics of Identifying Race in the New Genetics* (National Research Service Award - National Institutes of Health). Award Recipient: Sandra Lee, Ph.D. 2000-03. \$127,900

*Fetal MRI: Patient Expectations, Clinical Experience and Decision-Making* (The Children's Health Initiative). PI: Judy Illes, Ph.D. 2002-2003. Total Funding: \$35,000

*From Transplant Medicine to Tissue Engineering: the Ethics of Using Human and Animal Materials* (The Greenwall Foundation). PI: Linda Hogle, Ph.D. 2000-02. Total Funding: \$189,000

*Genetics of Nicotine Addiction: Examining Ethics and Policy* (National Institutes of Health). PI: Barbara Koenig, Ph.D. 2002-05. Total Funding: \$1,200,000

*Getting the Word Out on the Human Genome Project: A Course for Physicians* (U.S. Department of Energy). PI: Sally Tobin, Ph.D. 1996-2002. Total Funding: \$786,000

*Initiative to Improve Palliative and End-of-Life Care for African-Americans* (North General Hospital). PI: LaVera Crawley, M.D. 2001-03. Total Funding: \$62,000

*Neuroethics: A Virtual Library* (The Dana Foundation). PI: Judy Illes, Ph.D. 2002. Total Funding: \$5000

*Neuroethics: Mapping the Field Conference* (The Dana Foundation). PI: Barbara Koenig, Ph.D. 2002. Total Funding: \$105,000

*Neuroethics: Mapping the Field Travel Support* (National Institutes of Health). PI: Barbara Koenig, Ph.D. 2002. Total Funding: \$40,000

*The New Genetics: Interactive Courseware for Physicians* (Robert Wood Johnson Foundation). PI: Sally Tobin, Ph.D. 2000-03. Total Funding: \$193,000

*Observing Death: Examining Bioethics* (The Greenwall Foundation). PI: Barbara Koenig, Ph.D. 2002. Total Funding: \$25,000

*Promoting Effective Communication and Decision-Making for Diverse Populations* (Agency for Healthcare Research and Quality). PI: Barbara Koenig, Ph.D. 2000-02. Total Funding: \$153,000

*Tissue Engineering: the Morphogenesis of a New Scientific Field* (National Science Foundation). PI: Linda Hogle, Ph.D. 2001-04. Total Funding: \$289,000

*Worlds Apart: An Educational Multimedia Project on Cross-Cultural Health* (The Greenwall Foundation, The Commonwealth Fund, The Arthur Vining Davis Foundation, The California Endowment). PI: Maren Grainger-Monsen, M.D. 2000-03. Total Funding: \$1,500,000

## **B. Pending Grant Applications**

*Adult-To-Adult Living Liver Transplantation: Physicians and Donors' Decision-Making Processes* (NIH Center for Diabetes, Digestive and Kidney Diseases). Linda Hogle, Ph.D.

*Advanced Neuroimaging: Ethical, Legal and Social Issues* (National Institutes of Health). Judy Illes, Ph.D.

*Differential Trust and Cancer Care within Black Subgroups* (National Cancer Institute). LaVera Crawley, M.D.

*Distributive Justice in Human Genetic Variation Research* (National Human Genome Research Institute Ethical, Legal and Social Implications Program). Sandra Lee, Ph.D.

*Ethical and Social Concerns In Adult-To-Adult Living Liver Transplantation* (Robert Wood Johnson Foundation). Linda Hogle, Ph.D.

*Evaluating Evidence In Novel Combination Products: Risk, Benefit and Protection of Human Subjects in Tissue Engineering Trials* (National Institutes of Health). Linda Hogle, Ph.D.

*Fetal Alcohol Syndrome: An Electronic Curriculum* (Centers for Disease Control). Sally Tobin, Ph.D.

*Research Ethics in Medical Device Development* (Office of Human Research Protection). Linda Hogle, Ph.D.

*Towards a New Vocabulary for Human Genetic Variation* (National Institutes of Health). Mildred Cho, Ph.D.

*Web-Based Research Integrity Training for Biomedical Engineers and Medical Device Researchers* (Office of Research Integrity). Linda Hogle, Ph.D.

## **C. Research Publications**

### **1. Books**

**Eaton, M.** Bioscience Business Ethics - Stanford University Press (in press).



**Greely, H.T.** California Advisory Committee on Human Cloning, Cloning Californians? (Sacramento, CA 2002)

Marshall P.A., **Koenig B.A.** Anthropology and Bioethics. Cambridge University Press, (under contract).

## 2. Book Chapters

**Cho, M.K.** (in press) Ethical, Legal and Social Issues in Pharmacogenomics. In: Pharmacogenomics, Nicholas Dracopoli, (Ed) John Wiley and Sons, New York.

Shafazand S., **Crawley L.M., Raffin T.A., and Koenig, B.A.** Withholding and Withdrawing Treatment: The Doctor-Patient Relationship and the Changing Goals of Care. In: Berger A., Portenoy R.K., and Weissman D.E.. In: Principles and Practice of Supportive Oncology 2<sup>nd</sup> ed. New York, NY: Lippincott Williams & Wilkins Publishers (2002).

**Crawley L.M.,** Marshall, P.A. and **Koenig, B.A.** Respecting Cultural Difference at the End of Life. In: Quill, T. and Snyder, L., (eds). Physician's Guide to End-of-Life Care. American College of Physicians-American Society of Internal Medicine (2001).

**Greely, H.T.** Ethical Issues in “The New Genetics.” In: The International Encyclopedia of Social and Behavioral Sciences. (3<sup>rd</sup> ed., forthcoming 2001).

**Greely, H.T.** Ethical Issues in the Human Genome Diversity Project. In: The Encyclopedia of Ethical, Legal and Social Issues in Biotechnology. (2000).

**Greely, H.T.** Individualizing Medicine Through Pharmacogenomics – Are There Ethical Concerns? In: The Business Case for Pharmacogenomics. (ed. N.S. Rudolph, Woburn, Mass. 2000).

**Hogle, L.F.** Social and Ethical Issues in the Development and Dissemination of Tissue Engineering. In: Legal and Regulatory Issues in Tissue Engineering. Helman, Kiki and David Smith (eds). New York: Academic Press (in press).

**Hogle, L.F.** Life/Time Warranty: Rechargeable Cells and Extendable Lives. In: Animation and Cessation: Changing Definitions of Life and Death in the Context of Biomedicine. Lock, M. and S. Franklin (eds.) Santa Fe: School of American Research (in press).

**Illes, J.,** Glover, G.H., Leung, A.N.C., Glazer, G.M. (In press) Faculty Mentoring in Academic Radiology: Individual and Institutional Gains Outweigh Overhead. In J.R. Jinkins (Ed.) *The Practical Radiologist's Companion: Advice to Academia and Private Practice.*

Marshall P.A, **Koenig B.A.** Ethnographic Methods. In: Methods in Medical Ethics, J. Sugarman & D. P. Sulmasy, eds., Washington, DC: Georgetown University Press, 2001.

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Strassberg A., **Koenig B.A.**, Shafer A. Medicine and the Arts: Commentary on The River Styx Runs Upstream. In: Ten Years of Medicine and the Arts: 100 Selections from Academic Medicine 1991-2001. L.R. Dittrich, editor. Washington, DC: Association of American Medical Colleges, 2001.

**Koenig B.A.**, Davies E. Cultural Dimensions of End-of-Life Care for Children. Commissioned by the Institute of Medicine for the report: End of Life Care for Children. Washington, DC: National Academy of Sciences, 2002.

McGee D.C., Weinacker A.B., **Raffin T.A.** "Ethical Concerns in Managing Critically Ill Patients." In: Parillo JE, Dellinger RP, eds. Critical Care Medicine: Principles of Diagnosis and Management in the Adult. Mosby Yearbook, 2001.

Krishna G., **Raffin T.A.** "Withdrawal of Life Support." In: Deitch MD, Vincent J-L, Windsor ACJ, eds. Sepsis and Multiple Organ Dysfunction, Harcourt Health Services 2002 (Submitted).

**Tobin, S.L.** Earning Tenure: Ten Recommendations. In: Career Advice for Life Scientists. Women in Cell Biology Committee, American Society for Cell Biology, 2002.

**Tobin, S.L.** Dealing with Unstable Colleagues. In: Career Advice for Life Scientists. Women in Cell Biology Committee, American Society for Cell Biology, 2002.

### 3. Articles

Henry, M.R., **Cho, M.K.**, Weaver, M.A. and Merz, J.F. (2002) DNA Patenting and Licensing. *Science* 297:1279.

Merz, J.F., Kriss, A.G., Leonard, D.G.B. and **Cho, M.K.** (2002) Diagnostic Testing Fails the Test: The Pitfalls of Patents are Illustrated by the Case of Hemochromatosis. *Nature* 415:577-579.

Merz, J.F., Magnus, D., **Cho, M.K.** and Caplan, A.L. (2002) Protecting Subjects' Interests in Genetics Research. *American Journal of Human Genetics* 70:965-971.

Klein, R.E., Chang, J.T., **Cho, M.K.**, Easton, K.L., Ferguson, R., Hewett, M., Lin, Z., Liu, Y., Liu, S., Oliver, D.E., Rubin, D.L., Shafa, F., Stuart, J.M. and Altman, R.B. (2001) Integrating Genotype and Phenotype Information: An Overview of the PharmGKB Project. *The Pharmacogenomics Journal* 1:167-170.

**Cho, M. K.** Conflicts Of Interest In MRI: Issues in Clinical Practice and Research. (2002). In: J. Illes (Ed) "Emerging Ethical Issues in MRI". *Topics in Magnetic Resonance Imaging* 13:73-78.

**Cho, M. K.,** Shohara, R., and Rennie, D. (2001) What is Driving Policies on Faculty Conflict of Interest? Considerations for Policy Development. Investigating Research Integrity: Proceedings of the First ORI Research Conference on Research Integrity; Nicholas H. Steneck & Mary D. Scheetz (Eds).

**Crawley L.M.,** Marshall, P.A., Lo, B., **Koenig, B.A.,** Strategies for Culturally Effective End-of-Life Care. *Annals of Internal Medicine* 2002; 136(9):673-9.

**Crawley L.M.** African-American Participation in Clinical Trials: Situating Trust and Trustworthiness. *Journal of the National Medical Association* 2001; 93:14S-17S.

**Crawley L.M.** The Initiative to Improve Palliative Care for African-Americans. *SGIM Forum*. 2001 December 24(12)6-7.

**Greely, H.T.** Ethical Issues in Human Population Genetics. *The Annual Review of Genetics* (2001).

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**Greely, H.T.** Pharmacogenomics: Promise, Prospects, and Potential Problems. *Medical Ethics* vol. 9, issue 1, 1-2, 8 (Winter 2002).

**Greely, H.T.** Neuroethics? *Health Law News* (Summer 2002).

**Greely, H.T.** "Genotype Discrimination": The Complex Case for Some Legislative Protection. *Penn Law Review*:1483-1505 (May 2001).

**Greely, H.T.** Human Genomics Research: New Challenges for Research Ethics. *Perspectives in Biology and Medicine* 44(2):221-229 (Spring 2001).

Whitney, S.N., Brown, B.W., Brody, H., Alcsér, K., Bachman, J., **Greely, H.T.** Views of United States Physicians and Members of the American Medical Association House of Delegates Toward Physician-Assisted Suicide. *Journal of General Internal Medicine* 16(5):290-296 (May 2001).

**Greely, H.T.** Human Genome Diversity: What About the Other Human Genome Project? *National Review of Genetics* 222-227 (March 2001).

**Hogle, L.F.** (In press) Public Good, Private Protections: Competing Values In German Transplantation Law. *Law and Policy*.

**Hogle, L.F.** (ed.) Jurisdictions of Authority and Expertise in Science and Technology: Introduction. *Medical Anthropology* 21(3-4): 231-246. (2002).

**Hogle, L.F.** Reinventing Pharmaceutical Regulation: Whose Expertise Counts? *Medical Anthropology* 21(3-4): 275-306. (2002).

**Hogle, L.F.** Feminist Theory and Reproductive Medicine (review of *Body Talk*, M. Lay, L. Gurak, C. Gravon and C. Myntti (eds) *Medical Anthropology Quarterly*. (2002).

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**Hogle, L.F.** Regulating Human Tissue Innovations: Hybrid Forms of Nature and Governmentality. *Science Sociale et Santé* 18:53-73 (2001).

**Illes, J.** (Ed.) (In press) *Brain and Cognition: Ethical Challenges in Advanced Neuroimaging*, Academic Press, New York.

**Illes, J.** and **Raffin, T.** (In press) Neuroethics: A New Discipline is Emerging in the Study of Brain and Cognition. In: J. Illes (Ed.) *Ethical Challenges in Advanced Neuroimaging*, *Brain and Cognition*.

**Illes, J.**, Desmond, J., Huang, L.F., **Raffin, T.**, Atlas, S. Ethical and Practical Considerations in Managing Incidental Neurologic Findings in fMRI. (In press). In: J. Illes (Ed.) *Ethical Challenges in Advanced Neuroimaging*. *Brain and Cognition*.

Moseley, M., Bammer, R., **Illes, J.** (In press) Diffusion Tensor Imaging of Cognitive Function. In: J. Illes (Ed.) *Ethical Challenges in Advanced Neuroimaging*. *Brain and Cognition*.

Golby A.J., Poldrack R.A., **Illes J.**, Chen D., Desmond J.E., Gabrieli J.D. (2002) Memory Lateralization in Medial Temporal Lobe Epilepsy Assessed by Functional MRI. *Epilepsia*. 43(8):855-63.

Kim, B.S., **Illes, J.**, Kaplan, R.T., Reiss, A., Atlas, S.W. (In press) Neurologic Findings in Healthy Children on Pediatric fMRI: Incidence and Significance. *American Journal of Neuroradiology*.

**Illes, J.** and Atlas S.W. (Eds.) (2002) *Topics in Magnetic Resonance Imaging: Ethical Issues in MR Imaging*. Lippincott Williams & Wilkins, New York. vol. 13(2).

**Illes, J.** and Atlas, S.W. (2002) Introduction and Commentary: Emerging Ethical Issues in MRI, In: J. Illes and S.W. Atlas (Eds.) *Topics in Magnetic Resonance Imaging: Ethical Issues in MR Imaging*. Lippincott Williams & Wilkins, New York. vol. 13(2), pp. 71-72.

**Koenig, B.A.** Multidisciplinary Rounds: The Challenge of Providing Culturally-Competent Cancer Care. *Cancer Practice*, 2001. 9(2):62-65.

**Lee S.S.J.**, Mountain J., **Koenig B.A.** The Meanings of “Race” in the New Genomics: Implications for Health Disparities Research. *Yale Journal of Health Policy, Law, and Ethics*, 2001. 1(1):33-75.

**Koenig, B.A.** Why Not Grant Primacy to the Family? *American Journal of Bioethics*, 2001. 1(3):33-34.

Drought T.S., **Koenig B.A.** (In press) “Choice” in End-of-Life Decision Making: Researching a Fact or a Fiction? *The Gerontologist*, 2002.

**Lee, S.S.J.** and **Koenig, B.A.** (In press) “Racial Profiling of DNA Samples: Will It Affect Scientific Knowledge of Human Genetic Variation?” Bertha Knoppers, Ed. *DNA Sampling: Populations and Communities*.

**Lee, S.S.J.** (In press) “Aged Bodies as Sites of Remembrance: Colonial Memories in Diaspora.” *Trauma and Memory*. Ed. Jill Bennett and Rosanne Kennedy.

**Lee, S.S.J.** (In press) “Genetics and Racial Minorities.” *Encyclopedia of Bioethics*. 3<sup>rd</sup> Ed. New York: Macmillan Publishing.

Henig N.R., Faul J.L., **Raffin T.A.** Biomedical Ethics and the Withdrawal of Advanced Life Support. *Ann Rev Med*. 2001, 52:79-92.

Chehab E.L., Panicker N., Alper P.R., Baker L.C., Wilson S.R., **Raffin T.A.** The Impact of Practice Setting on Physician Perceptions of the Quality of Practice and Patient Care in the Managed Care Era. *Arch Int Med.*, 2001; 161:202-211.

Skarbinski J., Walker H.K., Baker, L.C., Kobaladze A., Kirtava Z., Baker L.C., **Raffin T.A.** The Burden of Out-of-Pocket Payments for Health Care in Tbilisi, the Republic of Georgia. *JAMA* 2002; 287:1043-1049.

Vaszar L., Henig N., **Raffin T.A.** (In press). Ethical Issues in the Care of Severe End-Stage Neuromuscular Disease. *Sem Resp Crit Care Med*.

Vaszar L., Rosen G.D., **Raffin T.A.** (In Press). Pharmacogenomics and the Challenge to Privacy. *The Pharmacogenomics J.*

**Tobin, S.L.** (2002). Genetic Medicine: Surviving the Transition to Reap the Benefits. Will Lack of Knowledge, Limited Resources, and Penalties for Patients Continue to Create Obstacles on the Path to Life-Saving Genetic Medical Services? *The Atlas Insider 2: 1, 3*.

#### **4. Abstracts**

**Cho, M.K.**, Lin, Z., Klein, T., Altman, R. Methodology on Scrubbing Data in PharmGKB. Presented at the Pacific Symposium on Biocomputing 2001, Kohala Coast, HI.

**Illes, J.**, Kirschen, M., Gabrieli, J.D. Emerging Trends in fMRI: Ethical Implications for Research and Clinical Medicine, Society for Neuroscience, Orlando, FL, November 2002.

**Illes, J.**, Kim, B.S., Kaplan, R.T., Reiss, A., Atlas, S.W. Neurologic Findings in Healthy Children on Pediatric fMRI: Incidence and Significance, 10<sup>th</sup> Scientific Meeting of the International Society for Magnetic Resonance Imaging, Honolulu, HI, May, 2002.

Caron L., **Raffin T.A.**, Fishman J.R., **Koenig, B.A.** "Genetic Research on Smoking: Foreseeable Applications and Policy Issues." A Decade of ELSI Research, Bethesda, MD, January 2001, printed in *The Journal of Law, Medicine & Ethics*, Special Supplement to Volume 29:2. Summer 2001.

**Lee S.S.J.**, Mountain J., **Koenig B.A.** "Variation and the Category of "Race" in SNP's Research." A Decade of ELSI Research, Bethesda, MD, January 2001, printed in *The Journal of Law, Medicine & Ethics*, Special Supplement to Volume 29:2. Summer 2001.

**Tobin, S.L.** and Boughton, A. Getting the Word Out on the Human Genome Project: A Multimedia Course for Physicians. Poster and Computer Demonstration, Ninth DOE Genome Contractor-Grantee Meeting, January 2002.

**Tobin, S.L.** and Boughton, A. Getting the Word Out on the Human Genome Project. Platform presentation at NIH-Sponsored Conference: A Decade of ELSI Research. December 2001.

**Tobin, S.L.**, Boughton, A., Krueger, C. Opening Genetics and genomics to the Public. American Society for Cell Biology Meeting, December 2002.

#### **5. Internet/Multimedia**

**Cho, M.K.**, and McKee, M. (2002) Authorship in Biomedical Research: Realities and Expectations. *ScienceNextWave* (online)  
<http://nextwave.sciencemag.org/cgi/content/full/2002/02/27/6>

**Crawley, L.M.** Guest Editorial - Palliative Care in the African American Community. *Innovations in End-of-Life Care*. 2001 Sept.-Oct. 3(5) <http://www2.edc.org/lastacts/>

**Illes, J.** Enduring Qualities in Mentoring (2002). *Science NextWave*  
<http://nextwave.sciencemag.org/cgi/content/full/2002/03/26/10>.

**Tobin, S.L.** and Boughton, A. (2001). The New Genetics: Courseware for Physicians. Molecular Concepts, Applications, and Ramifications. Interactive, multimedia CD-ROM.

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**Tobin, S.L.** (2002). Interview and article about provider and public education of genetics and genomics. Featured Scientist, Incyte Genomics. <http://www.incyte.com>

**Tobin S.L.,** Jacobs, C., Ford, J., Boughton, A., Ritter, K., Bamber, D. and the Education Task Force (2002). Program for Applied Cancer Genetics Prototype: Education for Primary Care Physicians. Hereditary Non-Polyposis Colorectal Cancer. <http://www.stanfordcancergenetics.org/>

#### **IV. EDUCATION, SERVICE AND OUTREACH**

SCBE educational programs extend from student teaching and mentoring to distance-based learning. These include undergraduate and graduate courses across the campus and the hospital as well as seminars and symposia on a wide range of contemporary topics in biomedical ethics. Medical school education remains a primary focus, with bioethics taught as a vertical thread throughout the medical school curriculum. SCBE also is home to a filmmaker-in-residence program, supporting the cross-fertilization of bioethics and documentary filmmaking. Service and outreach include formal training and ethics advice to campus groups such as members of the Human Subjects Panels, development of web-based training modules in research ethics and conflicts of interest for campus-wide use, participation in University committees, service to national professional organizations, advice to local and national policy-makers, and outreach to the general public through lectures and the lay press.

SCBE staff administer the clinical bioethics program within Stanford Hospitals and Clinics, including leadership of the hospital's clinical ethics committee, twice weekly ethics rounds in the intensive care units, and consultation to individual patients, families and health care providers confronting moral conflicts and uncertainties.

##### **A. Stanford Teaching**

SCBE staff participated in or taught lectures in the following courses:

###### School of Medicine

- BIOC 118: Genomics, Bioinformatics and Medicine
- BIOMEDIN 234: Biomedical Genomics
- GEN 201: Human Genetics
- HRP 210: Health Law and Policy
- HRP 228: Molecular Epidemiology (“Ethical Issues in Epidemiological Research”)

- MED 224: Ethnicity and Medicine (“Race/Ethnicity and Trust”)
- MED 255: Responsible Conduct of Research
- MED 399: Research (Primary Faculty)
- MED: Preparation for Clinical Medicine
- PRECEPT Research Ethics (“Ethics and End-of-Life”)

#### Stanford Hospitals & Clinics

- Center for Education (Futility in Medical Treatment)
- Department of Pulmonary and Critical Care
- Department of Neurosurgery (Neuroimaging Research: Compelling Questions, Ethical Implications)
- Grand Rounds:
  - Biomedical Ethics
  - OBGYN
  - Pulmonary (VA)

#### Graduate School of Business

- GSBGEN 522: Ethical Issues in the Biotech Industry (“Direct-to-Consumer Advertising of Prescription Pharmaceuticals”)

#### School of Engineering

- CHEMENG 450: Introduction to Biotechnology
- ME 374: Biomedical Technology Innovation Fellows Program (“The ‘Other’ Market Research: Social, Ethical and Policy Issues in Device Development”)
- ME 382: Biomedical Device Design and Evaluation (“Social, Ethical and Policy Issues in Device Development”)
- ME 385: Introduction to Tissue Engineering (“Social, Ethical and Policy Issues in Tissue Engineering”)

#### School of Humanities

- ANTHSCI 174: Bioethics and Anthropology
- BIOSCI 109: The Human Genome
- CASA 1: Introduction to Cultural Anthropology (“The Role of Medical Anthropology in National Health Policy” and “Anthropology of Medicine: What Does a Medical Anthropologist Do?”)
- CASA 80: Race and Ethnicity in East Asia
- CASA 85: South Asian Diasporas: History, Culture and Politics
- CASA 95: Research in Anthropology
- CASA 143: Anthropology of Death and Dying
- EIS108: Ethics and the Professions (“Medicine as a Profession - Autonomy and Informed Consent”)
- HUMBIO 127: Seminar on Conducting Research (“Human Research in Third World Countries”)
- HUMBIO: Ethical Issues on Research in Human Subjects (“Ethical and Regulatory Issues In Tissue Engineering And Combination Products”)
- IHUM 46: Visions of Mortality



- LING 52Q: Stanford Introductory Dialogue: Doctor-Patient Communication
- SOC 141A: Social Class, Race/Ethnicity and Health (“The Meanings of ‘Race’ in the New Genomics”)

#### Other

- “Teaching Culture and End-of-Life Care” End-of-Life Care Stanford Faculty Development Program – Faculty
- “Formulas for Funding Success” - SUMC Mentoring Program
- Stanford University IRB Educational Series (“Deception in Research: Human Subjects Considerations, the Therapeutic Misconception” and “Research Ethics and Social Science Methods”)

### **B. Service on University Committees**

SCBE staff participated in and contributed to the following university committees and programs:

#### School of Medicine and Hospitals

- Bio-X Leadership Council
- Center for Primary Care and Outcomes Research (PCOR) and the Center for Health Policy (CHP)
- LPCH and UCSF School of Nursing: Cultural Advisory Committee (in support of study “Latino and Chinese Families in Pediatric Palliative Care”)
- LPCH Ethics Committee
- SHC Ethics Committee
- SHC Task Force on Patient Consent
- SoM Candidate Admissions
- SoM Conflict of Interest Committee
- SoM Department of Oncology: Chair, Education Task Force, Clinical Cancer Genetics Program
- SoM General Clinical Research Center: Medical Advisory Committee and Safety Monitoring Board
- SoM Med Scholars Program
- SoM Review Committee for Health Services Research Interdisciplinary Graduate Program
- SoM Tissue Bank Advisory Committee
- Stanford Brain Research Center
- Women’s Health at Stanford

#### University

- Center for Biodesign
- “Ethics in Society” Program Steering Committee
- The Research Institute of Comparative Studies in Race and Ethnicity (RICSRE) - Member, Executive Committee
- Stanford Center for Law and the Biosciences (Director)

- Stanford Human Genome Education Program (for high school teachers) - Member, Advisory Committee, “Leadership Alliances in the Biological Sciences”
- Stanford Program in Law, Science, and Technology
- Stanford University Committee on Research

### **C. Student Mentoring**

#### Medical School

- Ellan Fan (Medical Student) 6/01-6/02, “Consumer-driven imaging”
- Khaliah Johnson (Medical Student) "Race/Ethnicity and Trust in the Doctor-Patient Relationship"
- Micean Johnikan (Master’s Student -Epidemiology ) 2001-02, “Determination and Assessment of Motivational Factors in Human Subject Recruitment”
- Brian Kim, (Medical Student) 6/01-8/02, “Incidental findings on MRI”
- Matt Kirschen (MD/PhD Student), 1/02 - present, “Emerging Trends in fMRI”

#### Undergraduate

- Tera Agyepong (Honors Thesis) “A Comparison of Trust in Health Care between African-Americans and African Immigrants to the US” (2002)
- Aarthi Belani (Honors Thesis Advisor, Stanford Ethics in Society Program, 2000-2001) “Patients, Pills, and the Poor: The Health Rights Impact of the WTO Agreement on Trade-related Aspects of Intellectual Property Rights.”
- Samantha Illangasekare, Human Biology
- Portia Jackson, Honors Thesis, 2001) “Ethnography of African-American Women with Sarcoidosis”
- Daniel Kaufman (Honors Thesis 2002, Science, Technology and Society) “Societal and Ethical Issues in Pharmaceutical Drug Regulation”
- Rochelle Lee (Human Biology 2002) Neuroethics Library & Conference Intern
- Herbrina Sanders (Undergraduate Advisor, Human Biology, 2001-present)
- Lynn M. Yee (Undergraduate Advisor, Human Biology, 2001-present).

#### Other Student Mentoring

- Department of Cultural and Social Anthropology: Program in Comparative Studies in Race and Ethnicity
- Medical Anthropology topics (social and policy issues related to organ transplantation or the use of human tissue)

### **D. Public Service**

- California Senate Committee on Appropriations: Report of the California Advisory Committee on Human Cloning – Hearing
- California Senate Committee on Health: Regulation of Human Cloning – Hearing
- California Senate Committee on Health: Stem Cells and California Law – Hearing
- Institute of Medicine: Committee on Care of Children Who Die and Their Families

- Lasker Foundation - Forum on Biomedical Ethics
- Representative Oberstar House Bill [HR5139] “Living Well With Fatal Chronic Illness Act of 2002”
- Senators William Frist and Ted Kennedy: advisor for new Senate Bill “Quality of Care for Individuals With Cancer Act”
- U.S. Department of Health and Human Services: Secretary’s Advisory Committee on Genetic Testing
- U.S. Senate Judiciary Committee: Hearing on Human Cloning
- U.S. Representatives Lynn Rivers and Curt Weldon: Advisor for House Bills HR 3966 “Genomic Research and Diagnostic Accessibility Act” and HR 3967 “Genomic Science and Technology Innovation Act”

**E. State and National Boards and Committee Memberships**

- Advisory Committee for a National Medical Curriculum on Pain Care
- Affymetrix
- American Association for the Advancement of Science Program on Dialogue on Science, Ethics & Religion
- Americans for Better Care of the Dying
- Bay Area Biosciences Center
- California Advisory Committee on Human Cloning
- Case Western Reserve University
- Human Genome Diversity Project
- International Genetic Epidemiology Society
- The National Academies Committee on The Use of Third Party Toxicity Research with Human Research Participants, the Science, Technology, and Law Program
- National Human Genome Research Institute - Genetic Variation Consortium
- National Human Genome Research Institute Haplotype Mapping Project
- National Human Genome Research Institute - Non-Medical Applications of Genomics
- NIH Program Project on Human Genetic Variation
- National Institute of Neurological Diseases and Stroke/Office of Research Integrity Ad Hoc Study Section
- National Medical Association Biomedical Education and Research Division.
- Northern California Cancer Center
- Oregon Health Sciences University - Program of Research on End-of-Life
- Robert Wood Johnson Foundation - Last Acts Campaign
- Santa Clara County Medical Association
- Sarcoidosis Research Institute
- UCSF School of Nursing: Consultant on NIH-funded Genomic Nursing Training Program
- U.S. Department of Health and Human Services - Secretary’s Advisory Committee on Genetic Testing
- U. S. Department of Veterans Affairs: Genetic Tissue Banking Initiative, Cooperative Studies Program (CSP) Coordinating Center
- World Cell Line Collection 1

## **F. Editorial Boards and Major Assignments**

American Journal of Bioethics  
American Journal of Public Health  
Annals of Internal Medicine  
BioMed Central  
Clinical Genetics  
Community Genetics  
Journal of the American Medical Association  
Journal of General Internal Medicine  
Journal of Palliative Medicine  
Medical Anthropology  
Science  
Science & Engineering Ethics  
Science, Technology, and Human Values

## **G. Leadership in Professional Societies**

American Anthropological Association  
Americans for Better Care of the Dying  
American Society for Bioethics and Humanities  
American Society of Law, Medicine, and Ethics  
Association for Asian American Studies  
Association for Asian Studies  
Association for Behavioral Science and Medical Education  
Council on Nursing and Anthropology  
Hastings Center  
Initiative to Improve Palliative Care for African Americans  
National Medical Association Biomedical Education and Research Division.  
Society for Applied Anthropology  
Society for Cultural Anthropology  
Society for Medical Anthropology  
Society for Psychological Anthropology  
Society for the Social Study of Science  
Women in Neuroscience

## **H. Journal Review**

American Journal of Public Health  
Annals of Internal Medicine  
Archives of Internal Medicine  
Brain and Language  
Brain and Cognition  
Community Genetics

Current Pharmacogenomics  
End of Life Physician Education Resource Center  
Gerontologist  
Health  
Health Affairs  
Isis  
Journal of the American Medical Association  
Journal of General Internal Medicine  
Journal of Health, Policy and Law  
Journal of Palliative Medicine  
Medical Anthropology  
Medical Anthropology Quarterly  
Oxford University Press  
Science  
Science and Engineering Ethics  
Science, Technology and Human Values  
Social Science and Medicine  
Technology and Culture  
Theoretical Medicine and Bioethics  
Western Journal of Medicine

## **I. Grant Review**

The Council for the Humanities of the Netherlands Organisation for Scientific Research  
Genome Canada  
Greenwall Foundation  
Humanities and Social Science Research Council of Canada  
Manitoba Health Research Council  
Meyer Memorial Trust  
National Institutes of Health  
National Science Foundation  
Robert Wood Johnson Foundation  
Rockefeller Foundation  
University of California  
U.S. Veteran's Administration Health Care Service  
The Wellcome Trust

## **J. Conferences Organized**

Congressional Black Caucus Annual Legislative Conference Issue Forum: Improving Care for African Americans Near the End-of-Life (Washington, DC)  
  
Education in Genetic Ethics Conference (Stanford, CA)

Heritage, Health, and Hope Forum for the Initiative to Improve Palliative Care for African Americans (New York, NY)

Neuroethics: Mapping the Field (San Francisco, CA)

Rockefeller Foundation Workshop Innovia: Transnational, Translational Research in Medical Innovation (Bellagio, Italy)

## **K. National Lectures and Presentations**

Agency for Healthcare Research and Quality (AHRQ) and the National Endowment for the Humanities (NEH): *Setting A Research Agenda for Health and the Humanities* (Potomac, MD)

American Anthropological Association: *Comparative Diaspora Studies: Koreans in Japan and the United States* (Chicago, IL)

American Anthropological Association: *Building the Able-bodied Subject: The Anthropology of Bioengineered Futures* (New Orleans, LA)

American Anthropological Association: *Racial Profiling and the DNA: The Meaning of Difference in the New Genetics* (New Orleans, LA)

American Anthropological Association: *Jurisdictions of Authority and Expertise in Science and Medicine* (New Orleans, LA)

American Anthropological Association: *Constructing Race in Japan: Managing Stigma in Everyday Life* (San Francisco, CA)

American Association for the Advancement of Science Meeting: *The New Genetics: Medicine and the Human Genome* (Washington, DC)

American Society of Bioethics and Humanities: *Bioethicists, Biotech Corporations, and Conflicts of Interest* (Salt Lake City, UT)

American Society for Clinical Pharmacology and Therapeutics: *Ethical Issues in Pharmacogenetics* (Atlanta, GA)

Cold Spring Harbor Laboratory Genome Sequencing and Biology Meeting: *Social Implications of Genetic Difference* (Cold Spring Harbor, NY)

Cold Spring Harbor: *Integrating Genomics Technologies in Healthcare: Practice and Policy Challenges* (Cold Spring Harbor, NY)

Congressional Black Caucus Annual Legislative Conference: *Improving Care for African Americans Near the End-of-Life* (Washington, DC)

Duke Institute on Care at the End of Life Symposium: *Crossing Over Jordan: African Americans and Care at the End of Life* (Durham, NC)

European Association for Science and Technology Studies: *The Biopolitics of Organs and Tissues* (Salt Lake City, UT)

European Association for Science and Technology Studies: *Transforming Human Remains: Cultural Concepts of Waste and Human Biological Materials* (Salt Lake City, UT)

Foundation for Research in Economics and the Environment: *Ethical, Social, and Legal Issues in Human Genetics* (Salt Lake City, UT)

Foundation for Research in Economics and the Environment: *The Revolution in Human Genetics: Social and Legal Issues* (Gallatin Gateway, MT)

German Federal Ministry of Education and Research: *Access and Costs of Genetic Tests* (Berlin, Germany)

Georgia Institute of Technology: *Tissue Engineering* (Atlanta, GA)

Illinois Judiciary: *Legal and Social Issues in Human Genetics* (Chicago, IL)

Indiana University/Purdue University at Indianapolis - Program in Medical Humanities: *Human Cloning: Ethical, Legal, and Political Issues* (Indianapolis, IN)

Indiana University School of Medicine Department of Clinical and Molecular Genetics: *Iceland's Genetic Research Plan: Ethical and Legal Implications for Genotype/Phenotype Resources Worldwide* (Indianapolis, IN)

Initiative to Improve Palliative Care for African Americans: *Is Palliative Care a Legitimate Priority in the Face of Health Care Disparity* (New York, NY)

Intercultural Cancer Council and Baylor College of Medicine: *Barriers to Hospice and Palliative Care for African-Americans* (Washington, DC)

3<sup>rd</sup> International DNA Sampling Conference: *Ethical, Legal and Social Issues: Racial Profiling of DNA Samples: Will It Affect Scientific Knowledge of Human Genetic Variation?* (Montreal, Canada)

Memorial University of Newfoundland: *Commercialization of Human Genetics in Newfoundland* (St. John's, Newfoundland and Labrador, Canada)

National Human Genome Research Institute (NHGRI): *Beyond the Beginning: The Future of Genomics* (Warrenton, VA)

National Institutes of Health, Integrative Conference on End-of-life Research: *Can Guidelines Be Created for Limiting Treatments in Older Persons Who Have Seriously Diminished Quality of Life?* (Bethesda, MD)

National Institute of Human Genome Research Institute - Ethical, Legal, and Social Implications (ELSI) Program Decade in Review Conference: *Genetic Variation and the Category of "Race" in SNPs Research* (Bethesda, MD)

National Medical Association: *Ethics and Human Subjects Protection: Balancing Roles as Physician and Investigator; Ethical Issues of Pain Management and Effects on African Americans; and Communicating Bad News, Advance Directives, and Medical Futility: What We Need to Know* (Honolulu, HI)

Neuroscience Future Conference: *Social Implications of a Revolution in Human Neuroscience: An Early Survey from 2025* (London, UK)

Office of Research Integrity: *Policies on Conflicts of Interest at US Universities* (St. Louis, MO)

Pennsylvania State University: *Will 'Race' Matter in the New Genomic Medicine?* (Hershey, PA)

Presidential Sesquicentennial Conference on the Human Genome: *Conflicts of Interest in Biomedical and Genomics Research: The View from Academia* (Minneapolis, MN)

Secretary's Advisory Committee on Genetic Testing: *The New Genetics: Courseware for Physicians* (Washington, DC)

Society for the Social Study of Science: *Anticipating the Social: Accountability and Regulation in Technoscience* (Milwaukee, WI)

Society for the Social Study of Science: *Challenges of Research on Human Subjects* (Boston, MA)

Thomas Hart and Mary Jones Horning Endowment in the Humanities Lecture Series: *The Human Genome: Historical and Contemporary Issues in Science, Law, and Medicine* (Corvallis, OR)

University of Cambridge Invited Departmental Seminar: *Integration of Genetic Services into Health Care in The United States: A Cautionary Tale* (Cambridge, England)

University of Maine Libra Foundation Lecture in Bioethics: *Ethical and Social Issues in Human Genetics: An Overview* (Machias, ME)

University of Minnesota: The Florence Schorske Wald Lecturer (Minneapolis, MN)



University of Pittsburgh Survival Skills and Ethics Course: *Conflicts of Interest* (Snowmass, CO)

University of Texas Southwestern Medical Center Ethics Grand Rounds: *Genomics, Race, and Health Disparities Research* (Dallas, TX)

University of Utah: Cowan Lecturer (Salt Lake City, UT)

West Harlem Environmental Action (WE ACT) National Conference: *Human Genetics, Environment, and Communities of Color: Ethical and Social Implications* (New York, NY)

## **L. Local and Regional Lectures and Presentations**

Adaptive Business Leaders: *Presentation to Governing Board* (San Francisco, CA)

Affymetrix: *“Race” Matters in Genomic Medicine* (Sunnyvale, CA)

American Academy of Hospice and Palliative Medicine: *Heritage, Health and Hope: Summary of the African American Initiative to Improve Palliative Care--National Policy Forum and Dying and the African American: Studies of Patients and those that Serve Them* (Palm Springs, CA)

BIO Biotechnology Industry Organization: *Bioethicists and Biotech Companies* (San Diego, CA)

Cal Poly Pomona Annual CSU Biotechnology Symposium: *The New Genetics: Medicine and the Human Genome* (Pomona, CA)

Cerus Research Council: *Ethical Issues in the Biotechnology Industry* (Concord, CA)

Charter 100 Club: *Genetic Testing for Hereditary Breast Cancer Risk: Issues and Answers* (San Francisco, CA)

Endocrine Society: *Ethical, Legal, and Social Issues in Pharmacogenomics* (San Francisco, CA)

Hastings College of Law Symposium on Human Cloning: *Cloning and Government Regulation* (San Francisco, CA)

Health Care Law Society: *Regulating Health Care Privacy and Data Security Without Stifling* (San Francisco, CA)

Kaiser Oakland Genetics Grand Rounds: *New Technologies in Genetics and the Primary Care Physician* (Oakland, CA)

Lick-Wilmerding High School: *Genetics and Ethics* (San Francisco, CA)

Lucile Packard Hospital: *Social and Ethical Issues in Genetic Testing* (Stanford, CA)

National Medical Association Project IMPACT: *Clinical Trials and African Americans: Why Should We Care* (Los Angeles, CA)

Norwegian Research Council: *Ethical, Social, and Legal Issues Arising from the Revolution in Human Biological Sciences* (San Francisco, CA)

The Pacific Business Group on Health: *The Human Genome Project and the Future of Health Coverage* (San Francisco, CA)

Palo Alto Medical Foundation: *Challenges in Biomedical Ethics and Advanced Imaging* (Palo Alto, CA)

Peninsula Center for the Blind and Visually Impaired: *Stem Cell Transplants and Other Legal Issues that Affect Eye Research* (Palo Alto, CA)

Quest Program: *Human Cloning* (Stanford, CA)

Roche Pharmaceuticals: *Biomedical Ethics* (San Francisco, CA)

San Francisco Veterans Affairs: *Ethical Challenges in Advanced Medical Imaging* (San Francisco, CA)

Santa Clara University: *Legal and Regulatory Issues in Human Cloning, California Cloning: A Dialogue on State Regulation* (Santa Clara, CA)

Society for Medical Anthropology Spring Meeting: *Medical Anthropologists 'Doing' Policy: A Report from the Genetic Trenches* (San Francisco, CA)

Society for Medical Anthropology: *The Embodied Experience of Genetic Risk: Where Biomedical Knowledge Meets Bodies* (San Francisco, CA)

Society for Neuroscience Annual Meeting: *The Human Neuron Mouse: Ethical and Social Issues* (San Diego, CA)

SRI International: *Emerging Trends and Challenges in Advanced Neuroimaging* (Menlo Park, CA)

Stanford Alumni Club of Sonoma: *Human Cloning: Science, Policy, and Politics* (Santa Rosa, CA)

Stanford Department of Communication and the Peninsula Press Club: *Journalism and the Ethics of Disclosure: When What We Have a Right To Know Is Not Right To Publish* (Stanford, CA)

Stanford Department of Health Research and Policy: *Effects of Patenting Practices on Research* (Stanford, CA)

Stanford Foreign Graduate Student Orientation: *Human Cloning and Embryonic Stem Cells: Science, Policy, and Politics and Ethical, Legal, and Policy Issues in Human Cloning* (Stanford, CA)

Stanford Health in the Digital Age Conference: *Commentary on Trusted Systems and Genetic Research* (Stanford, CA)

Stanford Human Genetics Journal Club: *Patents and Genetics: The Current Status and its Consequences* (Stanford, CA)

Stanford John S. Knight Fellowship Program for Professional Journalists: *After the Human Genome* (Stanford, CA)

Stanford John S. Knight Fellows Seminar: *Ethical, Legal, and Social Issues in Human Genetics and After the Human Genome* (Stanford, CA)

Stanford Korean American Students' Conference: *Confucianism and Gender in Korean American Life* (Stanford, CA)

Stanford Parents' Weekend: *Stem Cells, Human Cloning, and Public Policy* (Stanford, CA)

Stanford Serra House Seminar: *Stem Cells and Human Cloning: Policy and Politics* (Stanford, CA)

Stanford University: *The European Patent Office Comes to Silicon Valley: Biotechnology and Research Tools Patents* (Stanford, CA)

Stanford Think Again Program: *Morality and Immortality* (Chicago, IL; New York, NY; Portland, OR; Seattle, WA; Dallas, TX)

Stanford University Medical Center: *The Meaning of 'Race' in the New Genomic Medicine* (Stanford, CA)

Stanford Vice Provost for Undergraduate Education: *Human Cloning and Stem Cell Research: Science, Policy, and Politics* (Half Moon Bay, CA)

UCLA Task Force on Conflict of Interest: *Policies on Faculty Conflict of Interest* (Los Angeles, CA)

UCSF: *Pain Management and End-of-Life Care: A Comprehensive Approach to Patient Care* (San Francisco, CA)

UCSF Medical School: *Cultural Issues in Organ Transplantation* (San Francisco, CA)

UCSF College of Nursing: *The New Genetics and the Future of Healthcare* (San Francisco, CA)

University of California, Irvine Department of Medicine Grand Rounds: *Will 'Race' Matter in the New Genomic Medicine?* (Irvine, CA)

VA Hospital Pulmonary and Critical Care Medicine Grand Rounds: *When is a Patient Dying?* (Palo Alto, CA)

Women's Organization of Los Altos/Los Altos Hills: *Science and Ethics Update* (Los Altos, CA)

World Association of International Studies Conference/Stanford University: *International Issues in Biotechnology and Globalization of Science* (Stanford, CA)

## **M. Media Appearances**

ABC Nightline  
Agence France Presse  
Atlantic Monthly  
Associated Press  
Business Week  
Chicago Daily Law Bulletin  
Chicago Tribune  
Contra Costa Times  
Dallas Morning News  
Durham Herald-Sun  
E Magazine  
The Financial Times  
Frankfurter Allgemeine Sonntagszeitung  
Journal of the American Medical Association.  
Knight-Ridder Tribune  
KPIX Channel 5  
KQED  
Los Angeles Times  
Mother Jones  
Nature  
National Public Radio  
New Crisis  
The New Republic  
New York Times  
Palo Alto Daily  
PBS: "The Gene Files"  
The Philadelphia Inquirer  
Richmond Times-Dispatch  
Sacramento Bee

Salon.com  
San Diego Business Journal  
San Francisco Chronicle  
San Francisco Examiner  
San Jose Mercury News  
Science  
Seattle Public Television  
Stanford Magazine  
The Scientist  
Tech TV  
Times of India  
The Wall Street Journal  
The Washington Post  
The Washington Times

## **V. SCBE STEERING COMMITTEE**

Henry Greely, J.D. - Chair  
C. Wendell and Edith M. Carlsmith Professor in Law

Thomas Andriacchi, Ph.D.  
Professor of Mechanical Engineering (Biomechanical Engineering) and of Functional Restoration

Paul Berg, Ph.D.  
Robert W. and Vivian K. Cahill Professor of Cancer Research, Emeritus

Ronald Davis, Ph.D.  
Professor of Biochemistry and Genetics

William Durham, Ph.D.  
Bing Professor of Human Biology

Victor Fuchs, Ph.D.  
Henry J. Kaiser, Jr., Professor of Economics and of Health Research and Policy, Emeritus

Linda Giudice, M.D.  
Stanley McCormick Memorial Professor in the School of Medicine

Mary Kane Goldstein, M.D.  
Associate Professor of Medicine (General Internal Medicine) and, by courtesy, of Health Research and Policy

Deborah M. Gordon, Ph.D.  
Associate Professor of Biological Sciences

William L. McLennan, Jr.  
Dean, Religious Life

Susan Okin, Ph.D.  
Marta Sutton Weeks Professor of Ethics in Society

Debra Satz, Ph.D.  
Director, Ethics in Society Program and Associate Professor of Philosophy and, by courtesy, of  
Political Science

Lucille Shapiro, Ph.D.  
Virginia and D. K. Ludwig Professor and Senior Fellow, by courtesy, at the Institute for  
International Studies

David Stevenson, M.D.  
Harold K. Faber Professor of Pediatrics and Senior Associate Dean for Academic Affairs and  
Professor, by courtesy, of Gynecology and Obstetrics

Philip A. Pizzo, M.D.  
The Carl and Elizabeth Naumann Professor for the Dean of the School of Medicine and  
Professor of Pediatrics and of Microbiology and Immunology

Lawrence Shuer, M.D.  
Associate Professor of Neurosurgery at the Stanford University Medical Center and Associate  
Dean for Clinical Affairs and Chief of Staff SHS