

## CURRICULUM VITAE

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### EDUCATION

J.D., Harvard Law School, Cambridge, Massachusetts, 1979.

M.S., Education, Indiana University, Bloomington, Indiana, 1975.

B.A., Psychology and Sociology, Indiana University, Bloomington, Indiana, 1973.

### PROFESSIONAL EXPERIENCE

Visiting Scholar, Bioethics Program, National Institutes of Health Clinical Center, Fall 2017.

Daniel Noyes Kirby Professor of Law Emerita, Washington University in St. Louis, 2017-present.

Professor of Law, Washington University in St. Louis, 2015-2017.

Daniel Noyes Kirby Professor of Law and Professor of Ethics in Medicine, Washington University in St. Louis, 2001-2015.

Visiting Research Scholar, University of Tokyo, June-July 2003.

Professor of Law and Professor of Ethics in Medicine, Washington University in St. Louis, 1998-2001.

Professor, School of Law and Center for Biomedical Ethics, School of Medicine, Case Western Reserve University, 1991-98.

Fellow, Program in Ethics and the Professions, Harvard University, 1992-93.

Associate Professor, School of Law and Center for Biomedical Ethics, School of Medicine, Case Western Reserve University, 1988-1991.

Assistant Professor, Center for Ethics, Medicine and Public Issues, Baylor College of Medicine, 1983-1988.

Bigelow Teaching Fellow, School of Law, University of Chicago, 1982-1983.

Law Clerk to United States District Court Judge James E. Doyle, Madison, Wisconsin, September, 1980-July, 1982.

Postdoctoral Fellow, National Institute of Mental Health Training Grant in Social Science Research Methods,

Psychiatry Department, University of Wisconsin-Madison, 1979-1981.

Summer Associate, LeBoeuf, Lamb, Leiby and MacRae, New York, New York, 1978.

Research Assistant to Professor A. James Casner, Harvard Law School, Cambridge, Massachusetts, 1977-1978.

Social Welfare Examiner, Department of Social Services, Ithaca, New York, 1976.

### COURSES TAUGHT

Law School:

Courses: Bioethics and Law; Regulating Drugs and Other Medical Technologies; Human Genome Project and the Law; Criminal Law

Seminars: Biomedical Research Law and Policy; Genetics Ethics, Law, and Policy

Medical School:

Undergraduate and Graduate Classes on Selected Topics in Medical Ethics and Research Ethics

Graduate School:

Basic Course for M.A. in Bioethics Program (CWRU)

### BOOKS

*Silent Partners: Human Subjects and Research Ethics*, New York: Oxford University Press, 2017, paperback forthcoming 2018.

*Malignant: Medical Ethicists Confront Cancer*, New York: Oxford University Press, 2012 (editor and contributor).

*The Human Use of Animals: Case Studies in Ethical Choice*, New York: Oxford University Press, 1998, 2d ed. 2008. Co-authored with F. Barbara Orlans, Ph.D., Tom L. Beauchamp, Ph.D., David B. Morton, D.V.M. & John P. Gluck, Ph.D.

*Bioethics and Law: Cases, Materials and Problems*, Second Edition, St. Paul, West Publishing Company, 2003. Co-authored with Michael H. Shapiro, Roy G. Spece & Ellen Wright Clayton.

*When Science Offers Salvation: Patient Advocacy and Research Ethics*, New York: Oxford University Press, 2001.

### LAW REVIEW ARTICLES

“A Fate Worse Than Death? How Biomarkers for Alzheimer’s Disease Could Affect End-of-Life Choices,” *Indiana Health Law Review* 12:651-69, 2015.

“The ‘Right to Try’ Investigational Drugs: Science and Stories in the Access Debate,” Symposium on Science Challenges for Law and Policy, *Texas Law Review* 93:1631-1657, 2015.

“What Subjects Teach: The Everyday Ethics of Human Research,” Symposium on Relationship-Centered Health

Care: Implications for Law and Ethics, *Wake Forest Law Review* 50:301-341, 2015.

“Public Preferences and the Challenge to Genetic Research Policy,” *Journal of Law and the Biosciences* 1:52-67, 2014.

“From Double Standard to Double Bind: Informed Choice in Abortion,” Symposium on Conflicting Interests in Reproductive Autonomy and Their Impact on New Technologies, *George Washington University Law Review*, 76:1599-1622, 2008.

“Schiavo and Contemporary Myths about Dying,” Symposium on the *Schiavo* Case: Interdisciplinary Perspectives, *University of Miami Law Review*, 61:821-846, 2007.

“Precommitment: A Misguided Strategy for Securing Death With Dignity,” Symposium on Precommitment Theory, Bioethics, and Constitutional Law, *Texas Law Review*, 81:1823-1847, 2003.

“Patient Advocates in Research: New Possibilities, New Problems,” Daniel Noyes Kirby Chair Installation Address, *Washington University Journal of Law and Policy*, 11:237-248, 2003. Excerpts reprinted in *Medical Law: Text Cases and Materials*, E. Jackson, Oxford: Oxford University Press, 2006.

“The Ethics of Genetic Intervention: Human Research and Blurred Species Boundaries,” Symposium on Genes and the Just Society, *San Diego Law Review*, 39:739-748, 2002.

“Dementia Research: Ethics and Policy for the 21st Century,” Symposium on Legal and Ethical Issues in the Progression of Dementia, *Georgia Law Review*, 35:661-690, 2001.

“Breast Implants Revisited: A Response to Science on Trial,” *Wisconsin Law Review*, 1997:706-776. Co-authored with Wendy Wagner and Paul Giannelli.

“Missing Persons: Legal Perceptions of Incompetent Patients,” *Rutgers Law Review*, 46:609-719, 1994.

“Culpability and Other Minds,” *Southern California Interdisciplinary Law Journal*, 2:41-88, 1992.

“Personal Identity and Punishment,” *Boston University Law Review*, 70:395-446, 1990.

“Relitigating Life and Death,” *Ohio State Law Journal*, 51:426-437, 1990.

“Ethical and Legal Issues in Patenting New Animal Life,” *Jurimetrics Journal*, 28:399-435, 1988.

“Assessing Harm and Justification in Animal Research: Federal Policy Opens the Laboratory Door,” *Rutgers Law Review*, 40:723-795, 1988.

“Life, Death, and Incompetent Patients: Conceptual Infirmitities and Hidden Values in the Law,” *Arizona Law Review*, 28:373-405, 1986.

“Research on Animals: Values, Politics, and Regulatory Reform,” *Southern California Law Review*, 58:1147-1201, 1985.

“Feeding the Hunger Artists: Legal Issues in Treating Anorexia Nervosa,” *Wisconsin Law Review*, 1984:297-374.

“Ulysses and the Psychiatrists: A Legal and Policy Analysis of the Voluntary Commitment Contract,” *Harvard Civil Rights-Civil Liberties Law Review*, 16:777-854, 1982.

Review Essay, “Metaphysics and Morals: Moore's Medicine for a Misunderstood Marriage,” *American Bar*

*Foundation Research Journal*, 1985:917-26 (reviewing Moore, *Law and Psychiatry: Rethinking the Relationship*).

Review Essay, "Respecting and Protecting Nonhuman Animals: Regan's *The Case for Animal Rights*," *American Bar Foundation Research Journal*, 1984:831-50.

#### ARTICLES AND BOOK CHAPTERS

"Putting the Ethical Principles into Practice," in *Principles of Animal Research Ethics*, Tom Beauchamp and David DeGrazia eds., Oxford University Press, forthcoming.

"Advance Directives and Discrimination against People with Dementia," *Hastings Center Report*, forthcoming.

"Experimentation without Representation," *IRB: Ethics & Human Research*, 40:3-7, March-April, 2018.

"Advance Euthanasia Directives: A Controversial Case and Its Ethical Implications," *Journal of Medical Ethics*, 2016, <http://jme.bmj.com/content/early/2018/03/03/medethics-2017-104644>.

Co-authored with David Miller and Scott Kim.

"Preferences for Learning Different Types of Genome Sequencing Results among Young Breast Cancer Patients: Role of Psychological and Clinical Factors," *Translational Behavioral Medicine*, 8:71-79, 2018 (co-author).

"Dementia, Dignity, and Physician-Assisted Death," in *Human Dignity and Assisted Death* 105-22, Sebastian Muders ed., Oxford University Press, 2017.

"On Legalizing Physician-Assisted Death for Dementia," *Hastings Center Report*, 47: 5-6, July-August 2017.

"A Deep Dive into Community Engagement," *Narrative Inquiry in Bioethics*, 7(1):41-45, Spring 2017.

"Inclusion, Access, and Civility in Bioethics," *Hastings Center Report*, 47 (Special Supplement): 46-49, May-June 2017.

"A Tale of Two Disciplines: Law and Bioethics," *Perspectives in Biology and Medicine*, 60:47-59, Winter 2017.

"First-in-Human HIV-Remission Studies: Reducing and Justifying Risk," *Journal of Medical Ethics*, 43:78-81, 2017.

"Medicare and Advance Planning: The Importance of Context," *Hastings Center Report*, 46:5-6, May-June, 2016.

"Preferences for Return of Incidental Findings from Genome Sequencing among Women Diagnosed with Breast Cancer at a Young Age," *Clinical Genetics*, 89:378-84, 2016 (co-author).

"Autonomy and Its Limits in End-of-Life Law," in *Oxford Handbook of U.S. Healthcare Law* 399-420, I. G. Cohen, A. Hoffman & W. Sage eds., Oxford University Press, 2016,.

"'Right to Try' Laws: The Gap between Experts and Advocates," *Hastings Center Report*, 45:9-10, May-June 2015.

"Research Subjects' Voices: The Missing Element in Research Ethics," *Anaesthesia & Intensive Care* 43:297-99, 2015.

"Substituted Judgment in Real Life," *Journal of Medical Ethics*, 41:731-32, 2015.

"Treatment Decisions and Changing Selves," *Journal of Medical Ethics*, 41:975-76, 2015.

“Pre-Emptive Suicide, Precedent Autonomy, and Preclinical Alzheimer Disease,” *Journal of Medical Ethics*, 40:550-51, 2014.

“Personal Knowledge and Study Participation,” *Journal of Medical Ethics*, 40:471-74, 2014.

“Toward a Humane Death with Dementia,” *Hastings Center Report*, 44:38-40, May-June 2014.

“Law, Ethics, and the Patient Preference Predictor,” *Journal of Medicine and Philosophy*, 39:178-86, 2014.

“Edmund Pellegrino and the Art of Civilized Dialectics,” *Kennedy Institute of Ethics Journal*, 24:113-19, 2014.

“Drugs and the Death Penalty,” *Hastings Center Report*, 44:9-10, January-February 2014.

“Subversive Subjects: Rule-Breaking and Deception in Clinical Trials,” *Journal of Law, Medicine & Ethics*, 41:829-40, 2013.

“A Terrifying Truth,” *Narrative Inquiry in Bioethics*, 3:10-12, Spring 2013.

“Drug Compounding, Drug Safety, and the First Amendment,” *Hastings Center Report*, 43:9-10, March-April 2013.

“Building an Ethical Foundation for First-in-Human Nanotrials,” *Journal of Law, Medicine & Ethics*, 40:802-08, 2012.

“Alive and Well: The Research Imperative,” *Journal of Law, Medicine & Ethics*, 40:915-21, Winter 2012.

“Aligning Regulations and Ethics in Human Research,” *Science*, 337:527-28, August 3, 2012.

“A Status Elevation for Great Apes,” *Hastings Center Report*, 42:10-11, March-April 2012.

“Dignity Can Be a Useful Concept in Bioethics,” in *Bioethics, Public Moral Argument, and Social Responsibility* 45-54, M. Hyde and N. King, eds., Routledge Press, 2012.

“Bioethics and Cancer: When the Professional Becomes Personal,” *Hastings Center Report*, 41:14-18, November-December 2011.

“Families and Forensic DNA Profiles,” *Hastings Center Report*, 41:11-12, May-June 2011.

“Brain Imaging and Courtroom Deception,” *Hastings Center Report*, 40:7-8, November-December 2010.

“Suicide Attempts and Treatment Refusals,” *Hastings Center Report*, 40:10-11, May-June 2010.

“Stem Cell Research as Innovation: Expanding the Ethical and Policy Conversation,” *Journal of Law, Medicine and Ethics*, 38:332-341, 2010.

“Toward a Richer Public Bioethics,” in *Apples of Gold in Pictures of Silver: Honoring the Work of Leon R. Kass* 109-121, Y. Levin, T. Merrill, & A. Schulman, eds., Lanham, Maryland: Rowman & Littlefield, 2010.

“Irrational Basis: The Legal Status of Medical Marijuana,” *Hastings Center Report*, 39:7-8, November-December 2009.

“Off-Label Prescribing: A Call for Heightened Professional and Government Oversight,” *Journal of Law, Medicine and Ethics*, 37:476-486, 2009. Co-authored with Joel Frader, M.D.

“Prenatal Testing and Disability: A Truce in the Culture Wars?” *Hastings Center Report*, 39:7-8, May-June 2009.

“Priority Setting in Biomedical Research,” *Virtual Mentor, American Medical Association Journal of Ethics*, 11: 322-325, April 2009. Available at <http://www.virtualmentor.org>.

“First-in-Human Trial Participants: Not a Vulnerable Population, But Vulnerable Nonetheless,” *Journal of Law, Medicine and Ethics*, 37:38-50, 2009.

“Germline Genetic Modification” in *Medical Enhancement and Posthumanity* 191-205, B. Gordijn & R. Chadwick, eds., United Kingdom: Springer, 2008.

“Neuroscience’s Uncertain Threat to Criminal Law,” *Hastings Center Report*, 36:9-10, November-December 2008.

“The Limits of Apology Laws,” *Hastings Center Report*, 38:6-7, May-June 2008.

“Dignity and the Seriously Ill Patient,” in *Human Dignity and Bioethics* 505-12, President’s Council on Bioethics, 2008, reprinted, University of Notre Dame Press, 2009.

“The Role of the Public and Interest Groups in Research,” in *Oxford Textbook of Clinical Research Ethics* 231-41, E. Emanuel et al., eds., New York: Oxford University Press, 2008.

“Protecting Women from Their Abortion Choices,” *Hastings Center Report*, 37:13-14, November-December 2007.

“The Curious Case of Off-Label Use,” *Hastings Center Report*, 37:9-11, May-June 2007.

“Treatment Decisions for Incapacitated Patients,” in *Principles of Health Care Ethics* 305-10, R. Ashcroft, et al., eds., London: John Wiley & Sons, 2d ed. 2007.

“Investigational Drugs and the Constitution,” *Hastings Center Report*, 36:9-10, November-December 2006.

“Private-Sector Research Ethics: Marketing or Good Conflicts Management?” *Theoretical Medicine and Bioethics*, 27:115-39, 2006.

“Preimplantation Genetic Diagnosis as Medical Innovation: Reflections from the President’s Council on Bioethics,” *Fertility & Sterility*, 85:1633-37, 2006.

“Pharmaceutical Company Gifts: From Voluntary Standards to Legal Demands,” *Hastings Center Report*, 36:8-9, May-June 2006.

“Professionals, Conformity, and Conscience,” *Hastings Center Report*, 35:9-10, November-December 2005.

“Schiavo’s Legacy: The Need for an Objective Standard,” *Hastings Center Report*, 35:20-22, May-June 2005.

“A New Era in Drug Regulation?” *Hastings Center Report*, 35:10-11, May-June 2005.

“Stem Cell Research: The Bigger Picture,” *Perspectives in Biology and Medicine*, 48:181-94, 2005.

“Research Ethics and Maternal-Fetal Surgery,” in *Ethics and Research with Children: A Case-Based Approach* 223-40, R. Kodish, ed., New York: Oxford University Press, 2005.

“Plan B: Values and Politics at FDA, Again,” *Hastings Center Report*, 33:9-10, November-December 2004. Reprinted in *Ethics Across the Professions: A Reader for Professional Ethics* 414-16, C. Martin, W. Vaught & R.

Solomon, eds., New York: Oxford University Press, 2010.

“Death with Dignity: Contested Boundaries,” *Journal of Palliative Care*, 20:201-06, 2004.

“Designing Babies: Human Research Issues,” *IRB: Ethics & Human Research*, 26:1-8, September-October 2004.

“*Schiavo*: A Hard Case Makes Questionable Law,” *Hastings Center Report*, 33:8-9, May-June 2004.

“Genetic Modification of Preimplantation Embryos: Toward Adequate Human Research Policies,” *Milbank Quarterly*, 82:195-214, 2004.

“Research Oversight and Adults with Cognitive Impairment,” *Hastings Center Report*, 33:9-10, November-December 2003.

“Human Cloning and the FDA,” *Hastings Center Report*, 33:7-8, May-June 2003.

“Ethical and Policy Issues in Research on Elder Abuse and Neglect,” in Panel to Review Risk and Prevalence of Elder Abuse and Neglect, National Research Council, *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America* 303-338, R. Bonnie & R. Wallace, eds, Washington, DC: National Academy Press, 2003.

“Protecting Posthumous Children,” *Hastings Center Report*, 32:8-9, November-December 2002.

“The Conscious Incompetent Patient,” *Hastings Center Report* 32:9-10, May-June 2002.

“The Ubiquity and Utility of the Therapeutic Misconception,” *Social Philosophy & Policy* 19:271-294, 2002. Excerpt reprinted in *The Ethics and Regulation of Human Subjects Research*, C. Coleman et al. eds., LexisNexis, 2005.

“Procreation and Punishment,” *Hastings Center Report* 31:8-9, November-December 2001.

“Defining Research Misconduct: Will We Know It When We See It?” *Hastings Center Report* 31:31-32, May-June 2001.

“Research Subjects with Mental Disabilities: The More Things Change . . .,” in *Mental Health Law in Evolution: A 25-Year Retrospective 1972-1997* 57-74, L. Frost & R. Bonnie, eds., Washington, DC: American Psychological Association, 2001.

“Advance Directives as Acts of Communication: A Randomized Controlled Trial,” *Archives of Internal Medicine*, 161:421-430, 2001. Co-authored with colleagues in grant project, “Testing the Effectiveness of Advance Directives.”

“Advance Directives in Dementia Research: Promoting Autonomy and Protecting Subjects,” *IRB: Ethics & Human Research*, 23:1-6, January-February 2001.

“Regulating Assisted Reproduction,” *Hastings Center Report*, 30:26-27, November-December 2000.

“The Supreme Court and End-of-Life Care: Principled Distinctions or Slippery Slope?” in *Law at the End of Life: The Supreme Court and Assisted Suicide* 83-100, C. Schneider, ed., Ann Arbor: University of Michigan Press, 2000.

“Government Priorities for Biomedical Research: What Does Justice Require?” in *Current Legal Issues: Law and Medicine*, 3:399-419, M. Freeman & A. Lewis, eds., Oxford: Oxford University Press, 2000.

“Accountability in Science and Government: Is Access the Answer?” *Hastings Center Report*, 30:29-30, May-

June 2000.

"Planning for Future Research Participation: Ethical and Practical Considerations," *Accountability in Research* 7:129-36, 1999. Reprinted in *Research and Decisional Capacity: Responding to the National Bioethics Advisory Commission*, A. Shamoo, ed., New York: Taylor & Francis, 2002.

"Dementia and Advance Care Planning: Perspectives from Three Countries," *Journal of Clinical Ethics* 10:271-85, 1999 (with several co-authors).

"Should Consent Be Required for an HIV Test?" in *Ethical Dilemmas in Neurology* 13-21, A. Zemon & L. Emanuel, eds., London: W.B. Saunders, 2000.

"Surfing for Studies: Clinical Trials on the Internet," *Hastings Center Report*, 29: 26-27, November-December 1999.

"Funds for Research on Conditions Primarily Affecting Women: What Is a 'Fair Share'?" *Journal of Gender-Specific Medicine*, 2:23-26, September-October 1999.

"Public Advocacy and Allocation of Federal Funds for Biomedical Research," *Milbank Quarterly*, 77: 257-274, 1999.

"Criminal Responsibility and the 'Genetics Defense,'" in *Genetics and Criminality: Perspectives from Science, Philosophy and Law* 163-73, J. Botkin, W. McMahon & L Francis, eds., Washington, DC: American Psychological Association, 1999.

"Science in the Courtroom: A New Approach," *Hastings Center Report*, 29:26-27, May-June 1999.

"Community Representatives and Nonscientists on the IACUC: What Difference Should It Make?" *ILAR Journal*, 40:29-33, 1999.

"Time for New Rules on Human Subjects Research?" *Hastings Center Report*, 28:23-24, November-December 1998.

"Setting Priorities for Science Support," *Hastings Center Report*, 28:24-26, May-June 1998.

"The Rule of Double Effect: A Critique of Its Role in End-of-Life Decision Making," *New England Journal of Medicine*, 337:1768-1771, 1997. Co-authored with Timothy Quill, M.D. and Dan Brock, Ph.D.

"Scientists in the Sunshine," *Hastings Center Report*, 27:26-18, November-December 1997.

"Giving Scientists Their Due: The Imanishi-Kari Decision," *Hastings Center Report*, 27:26-28, May-June 1997.

"Long-Term Contraceptives in the Criminal Justice System," in *Coerced Contraception? Moral and Policy Challenges of Long-Acting Birth Control* 134-150, E. H. Moscovitz & B. Jennings, eds., Washington: Georgetown University Press, 1996.

"Still Troubled: In re Martin," *Hastings Center Report*, 26:21-22, July-August 1996.

"Mentally Disabled Research Subjects: The Enduring Policy Issues," *Journal of the American Medical Association*, 276:67-72, 1996. Excerpt reprinted in *The Ethics and Regulation of Research with Human Subjects*, C. Coleman et al., eds., LexisNexis, 2005.

"What Bioethics Can Learn from the Women's Health Movement," in *Feminism and Bioethics* 144-159, S. Wolf,



ed., New York: Oxford University Press, 1996.

"And Baby Makes Three... or Four... or Five: Assisted Reproduction," *Trial*, 32:28-33, December 1995.

"Dworkin on Dementia: Elegant Theory, Questionable Policy," *Hastings Center Report*, 25:32-38, November-December 1995. Reprinted in *Bioethics*, Justin Oakley, ed., Surrey, England: Ashgate, 2009, in *Bioethics: An Anthology* 312-320, P. Singer & H. Kuhse, eds., Malden, Massachusetts: Blackwell Publishers, 1999, in *Meaning and Medicine: A Reader in the Philosophy of Health Care*, J. Lindemann Nelson and H. Lindemann Nelson, eds., New York: Routledge, 1999.

"Long-Term Contraceptives in the Criminal Justice System," *Special Supplement, Hastings Center Report*, 25:S15-S18, January-February 1995. Reprinted in *Taking Sides: Clashing Views on Controversial Bioethical Issues*, C. Levine, ed., Guilford, Connecticut: Dushkin Publishing Group, 1997.

"Advance Directives: Implications for Policy," Special Supplement, *Hastings Center Report*, 24:S2-S5, November-December 1994.

"Product Liability Considerations," in National Heart, Lung and Blood Institute, *Report of the Workshop on the Artificial Heart: Planning for Evolving Technologies* 97-101, 1994.

"Freedom of Conscience, Professional Responsibility, and Access to Abortion," *Journal of Law, Medicine & Ethics*, 22:280-285, 1994. Reprinted in *Abortion*, B. Bennett, ed., International Library of Medicine, Ethics and Law, London: Ashgate Publishing Group, 2004 and *Bioethics, Justice, and Health Care* 464-472, W. Teays & L. Purdy, eds., Belmont, California: Wadsworth/Thompson Learning, 2000.

"The Incompetent Patient on the Slippery Slope," *Hastings Center Report*, 24:6-12, July-August 1994. Co-authored with Peter J. Whitehouse, M.D., Ph.D. Reprinted in *Social Issues Resources Series* and in *Medical Ethics*, M. Weinberg, ed., Amherst, New York: Prometheus Books, 2000.

"The Public Context of Private Medical Decisions," *Hastings Center Report*, 24:21-22, May-June 1994.

"Sanctions for Research Misconduct: A Legal Perspective," *Academic Medicine*, 68:539-543, September 1993.

"Defining Scientific Misconduct: The Relevance of Mental State," *Journal of the American Medical Association*, 269:895-97, 1993.

"Values and Perspectives on Abuse: Unspoken Influences on Ethical Reasoning," in *Ethical Conflicts in the Management of Home Care* 121-127, R. Kane & A. Caplan, eds., New York: Springer, 1993.

"Standards for Animal Research: Justification and Assessment for Alternatives," *Journal of the American Veterinary Medical Association*, 200:667-69, 1992.

"Wanted: Single, White Male for Medical Research," *Hastings Center Report*, 22:24-29, January-February 1992. Reprinted in *The Ethical Dimensions of the Biological Sciences*, R. Bulger, E. Heitmen & S. Reiser, eds., New York: Cambridge University Press, 1993, in *Ethical Issues in Modern Medicine*, J. Arras & B. Steinbock, eds., Mountain View, California: Mayfield Publishing Company, 1995, in *Ethical and Regulatory Aspects of Clinical Research* 166-71, E. Emanuel et al., eds., Baltimore: Johns Hopkins University Press, 2003; and in *The Ethics and Regulation of Human Subjects Research*, C. Coleman et al., eds., LexisNexis, 2005.

"Autonomy Revisited: The Limits of Anticipatory Choices," in *Dementia and Aging: Ethics, Values and Policy Choices* 71-85, R. Binstock, S. Post & P. Whitehouse, eds., Baltimore: Johns Hopkins University Press, 1992.

"Making Up Our Minds: Can Law Survive Cognitive Science?" *Criminal Justice Ethics*, 10:27-40, Winter/Spring

1991.

"Institutional Animal Committees: Theory and Practice," in *The Experimental Animal in Biomedical Research* 49-63, B. Rollin, ed., Boca Raton, Florida: CRC Press, 1990.

"Review Standards for Animal Research: A Closer Look," *Institute of Laboratory Animal Resources News* (National Research Council), 32:2-7, 1990.

"Measuring Merit in Animal Research," *Theoretical Medicine*, 10:21-34, 1989.

"Quality of Life and Treatment Decisions for Incompetent Patients," *Law, Medicine & Health Care*, 17:234-44, 1989. Co-authored with John A. Robertson. Reprinted in *Ethical Issues in Modern Medicine*, B. Steinbock, J. Arras & A. London, eds., New York: McGraw-Hill, 2003 and in *Intervention and Reflection: Basic Issues in Medical Ethics*, R. Munson, ed., Wadsworth Publishing Company, 1999.

"Developing Standards in Animal Research Review," *Journal of the American Veterinary Medical Association*, 194:1184-1191, 1989.

"Ethical and Regulatory Considerations in the Use of Cold-Blooded Vertebrates in Biomedical Research," *Nonmammalian Animal Models for Biomedical Research* 369-376, A. Woodhead, ed., Boca Raton, Florida: CRC Press, 1989.

"Advance Directives, Self-Determination, and Personal Identity," *Advance Directives in Medicine* 155-170, C. Hackler, R. Mosley & D. Vawter, eds., New York: Praeger Publishers, 1989.

"Standards for Animal Research: Looking at the Middle," *Journal of Medicine and Philosophy*, 13:123-143, 1988.

"Withholding Medical Treatment from the Severely Demented Patient," *Archives of Internal Medicine*, 148:1980-1984, 1988. Co-authored with several colleagues at Baylor College of Medicine.

"Informed Consent in Emergency Care: Illusion and Reform," *Annals of Emergency Medicine*, 16:62-67, 1987. Co-authored with Eugene V. Boisaubin, Jr., M.D.

"Animal Research," *BioLaw: A Legal and Ethical Reporter on Medicine, Health Care, and Bioengineering* 253-71, J. Childress, P. King, K. Rothenberg & W. Wadlington, eds., Frederick, Maryland: University Publications of America, 1986 & 1990 supplement.

"Psychiatric Patients Who Refuse Nourishment," *General Hospital Psychiatry*, 8:101-06, 1986. Co-authored with Eugene V. Boisaubin, Jr., M.D.

"When Patients Resist Feeding: Medical, Ethical and Legal Considerations," *Journal of the American Geriatrics Society*, 33:790-94, 1985.

"Social Justice in New Reproductive Techniques," *Genetics and the Law III* 159-74, G. Annas & A. Milunsky, eds., New York: Plenum, 1985.

"Discontinuing Nutritional Support: A Review of the Case Law," *Journal of the American Dietetic Association*, 85:1289-92, 1985.

"Ethics, Law, and Nutritional Support," *Archives of Internal Medicine*, 145:122-24, 1985. Co-authored with Eugene V. Boisaubin, Jr., M.D.

"Legal and Policy Considerations in Treatment of Anorexia Nervosa," *International Journal of Eating Disorders*,

3:43-51, 1984.

"The Role of Advance Treatment Directives in Health Care Policy," *Proceedings of the Third International Conference on System Science in Health Care* 814-817, Eimeren, Engelbrecht & Flagle, eds., Berlin: Springer-Verlag, 1984.

"Bound to Treatment: The Ulysses Contract," *Hastings Center Report*, 14:13-16, June 1984.

"Refusing Electroshock Therapy," *Hastings Center Report*, 12:18, 20, December 1982.

"Deception Research and the HHS Final Regulations," *IRB: A Review of Human Subjects Research*, 3:3-4, April 1981.

#### OTHER PUBLICATIONS

"Advance Euthanasia Directives in the Spotlight," *Journal of Medical Ethics Blog*, March 5, 2018, <http://blogs.bmj.com/medical-ethics/2018/03/05/advance-euthanasia-directives-in-the-spotlight/>. Co-authored with David Miller and Scott Kim.

"Insights from Fictional Research Subjects," *Hastings Bioethics Forum*, January 11, 2017, <http://www.thehastingscenter.org/what-research-ethics-can-learn-from-fiction-writers-about-the-experience-of-participating-in-research>.

"Giving Subjects a Voice in Research Ethics and Oversight," *Ampersand*, December 20, 2016, <http://blog.primr.org/giving-subjects-voice-research-ethics-oversight/>.

"Patients in Research: What the Professionals Don't Get," *Harvard Bill of Health Blog*, December 16, 2016, <http://blogs.harvard.edu/billofhealth/2016/12/16/patients-in-research-what-the-professionals-dont-get/>.

"A Cure for Cancer?" *New York Times*, January 14, 2016 (letter).

"Commentary on Zvonareva et al., "Risks and Benefits of Trial Participation: A Qualitative Study of Participants' Perspectives in Russia," *Clinical Trials*, 12:654-56, 2015.

"Commentary on an Excerpt from *So Much for That*," *Medicine and the Arts, Academic Medicine*, 90:1052-53, 2015.

"Ethics Question on Ebola," *N.Y. Times*, Aug. 13, 2014 (letter).

"Human Dignity," in *Encyclopedia of Quality of Life and Well Being Research* 3021-22, A. Michalos ed., Dordrecht, Netherlands: Springer, 2014.

"Sunday Dialogue: Conversations between Doctor and Patient," *New York Times*, August 25, 2012 (letter and reply to readers' responses).

"Discussing Dying with Loved Ones," *New York Times*, [nytimes.com](http://nytimes.com), July 28, 2012 (letter).

"The Varieties of Consent," *Hastings Center Report*, 41:46-47, September-October 2011 (book review).

"Cancer: Still a Bad Metaphor," *Hastings Bioethics Forum*, <http://www.thehastingscenter.org>, September 6, 2011.

“Decision Fatigue,” *New York Times Magazine*, September 2, 2011 (letter).

“Sexuality and a Severely Brain-Injured Spouse,” *Hastings Center Report*, 40:3, May-June 2010 (commentary).

“Screen the Parents,” The Baby Market (*New York Times Room for Debate*, December 29, 2009), at <http://www.roomfordebate.blogs.nytimes.com>.

“States Should Set Firm Standards,” The Trouble with Twin Births (*New York Times Room for Debate*, October 11, 2009), at <http://www.roomfordebate.blogs.nytimes.com>.

“Substituting Authenticity for Autonomy,” *Hastings Center Report*, 39:3, March-April 2009 (commentary).

“Issues in Off-Label Use,” Outside the Operating Room—Economic, Regulatory, and Legal Challenges Panel, Proceedings of the Ethical Challenges in Surgical Innovation Summit, *Cleveland Clinic Journal of Medicine*, 75(6): S63-64 (2008) (conference proceedings).

“Off-Label Indications for Medication Use and the Published Literature,” *JAMA*, 300:1411, 2008 (letter).

“Research Ethics Comes of Age,” *Hastings Center Report*, 36:5, September-October 2008 (letter).

“Ethics and Clinical Trials,” [nytimes.com](http://nytimes.com), October 4, 2007 (letter).

“Confronting Early-Stage Alzheimer’s,” *New York Times*, April 2, 2007 (letter).

“Protection of Human Subjects and Scientific Progress: Can the Two Be Reconciled?” *Hastings Center Report*, 36:7, January-February 2006 (letter).

Contributor, *Taking Care: Ethical Caregiving in an Aging Society*, President’s Council on Bioethics, September 2005.

“Schiavo: Perspectives of an Ethics Professor,” *St. Louis Post-Dispatch*, March 27, 2005 (commentary).

“Women Who Donate Eggs for Research Also Deserve Premium Care,” *St. Louis Post-Dispatch*, March 1, 2005 (commentary).

“Clinical Trial Registration and the ICMJE,” *Journal of the American Medical Association*, 293:157, 2005 (letter).

“Stem Cells and Moral Questions,” *New York Times*, August 19, 2004, at A30 (letter).

“Bioethics, Science, and Politics,” *New England Journal of Medicine*, 351: 299, 2004 (letter).

“Wisdom in Self-Scrutiny,” *Science*, 304:1111, 2004 (letter).

“U.S. Science: Endangered Species?” *New York Times*, May 5, 2004, at A26 (letter).

“Subjects of the State,” *Nature Medicine*, 10:450, 2004 (book review).

Contributor, *Reproduction and Responsibility: The Regulation of New Biotechnologies*, President’s Council on Bioethics, March 2004.

Contributor, *Monitoring Stem Cell Research*, President’s Council on Bioethics, January 2004.

“Reeve and the Doctors,” *New Yorker*, December 1, 2003 (letter).

“Dispute in Schiavo Case Turns on Five Critical Questions,” *St. Louis Post-Dispatch*, November 17, 2003, at C7 (commentary)

Contributor, *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, New York: HarperCollins, 2003 (Report by the President’s Council on Bioethics).

“Standards for Family Decisions: Replacing Best Interests with Harm Prevention,” *American Journal of Bioethics*, Summer 2003, 54-55 (commentary).

“Double Trouble: Clonaid’s Baby Claims Should Breed Intense Suspicion within the Scientific Community,” *St. Louis Post-Dispatch*, January 5, 2003, at B3 (commentary).

“If This Child Is Truly a Clone ...,” *New York Times*, December 31, 2002, at A20 (letter).

“Must Research on Stem Cells Be Allowed?” *EIDON*, October, 2002, at 5 (Spanish health science ethics journal).

Contributor, *Human Cloning and Human Dignity: The Report of the President’s Council on Bioethics*, New York: Public Affairs, 2002.

“Beyond Government Intervention: Drug Companies and Bioethics,” *American Journal of Bioethics*, Summer 2002, 42-43 (commentary).

“Whose Words Are They?” *St. Louis Post-Dispatch*, March 25, 2002, at B7 (commentary).

“Brave New World,” *St. Louis Post-Dispatch*, February 18, 2002, at B9 (commentary).

“Embryonic Stem Cells: Expanding the Analysis,” *American Journal of Bioethics*, Winter 2002, at 40-41 (commentary).

“Donation, Disclosure, and Deception,” *American Journal of Bioethics*, Fall 2001, at 15-16 (commentary).

“Research with Respect,” *New York Times*, November 23, 2001, at A32 (letter).

“Financial Interests and Research Protections: Can They Coexist?” *Lahey Clinic Medical Ethics Newsletter*, Fall 2001, at 4, 8. Reprinted in *Biomedical Ethics: A Multidisciplinary Approach to Moral Issues in Medicine and Biology*, D. Steinberg, ed., Hanover: University Press of New England, 2007.

“Beyond Disability: Bioethics and Patient Advocacy,” *American Journal of Bioethics*, Summer 2001, at 50-51 (commentary).

“Bush’s Decision Reignited the Stem Cell Debate: Don’t Hype the Hope,” *St. Louis Post-Dispatch*, August 14, 2001, at B7 (commentary).

“What We Don’t Know Can Hurt Us: Human Testing Comes with a Price,” *St. Louis Post-Dispatch*, July 10, 2001, at B7 (commentary).

“Naive Expectations Endanger Biomedical Research,” *Chronicle of Higher Education*, July 6, 2001, at B12 (commentary).

“When the Hunt for a Cure Hits Close to Home,” *New York Times*, § 3, Money and Business, at 13, June 10, 2001 (letter).

“Payment to Research Participants: The Importance of Context,” *American Journal of Bioethics*, Spring 2001, at 47 (commentary).

“Cloning Animals: What (Who?) Is Next?” *New York Times*, March 28, 2001, at A22 (letter).

“Ethical Issues in Embryonic Stem Cell Research,” *Journal of the American Medical Association*, 285:1439, 2001 (letter).

“Cosmetic Infertility Services and Professional Integrity,” *American Journal of Bioethics*, Winter 2001, at 11-12 (commentary).

“Weighing the Benefits of New Alzheimer’s Treatments,” *Science*, 289:869, 2000 (letter).

“Help Doctors Who Help the Poor,” *New York Times*, August 6, 2000 (letter).

“Advance Research Directives: Implementation Issues,” *Journal of the American Geriatrics Society*, 48:859-60, 2000 (letter).

American Society for Reproductive Medicine Ethics Committee, “Financial Incentives in Recruitment of Oocyte Donors,” *Fertility and Sterility*, 74:216-20, 2000 (primary drafter).

“Covering Cancer Care,” *New York Times*, December 19, 1999, § 4, at 12 (letter).

“Research Involving Persons with Mental Disabilities: A Review of Policy Issues and Proposals,” in National Bioethics Advisory Commission, *Research Involving Persons with Mental Disorders That May Affect Decision-Making Capacity*, Commissioned Papers, 5-28, May 1999.

“Is Informed Consent Always Necessary for Randomized, Controlled Trials?” *New England Journal of Medicine*, 341: 449, 1999 (letter).

Consensus Statement, Alzheimer’s Disease International and International Working Group for Harmonization of Dementia Drug Guidelines, “Research Involving Human Subjects with Dementia,” *Alzheimer Disease and Associated Disorders*, 13:71-79, 1999 (one of two primary drafters).

“Animal Rights Review,” *Science*, 283:938, 1999 (letter). Co-authored with F. Barbara Orlans, Tom Beauchamp, David Morton and John Gluck.

Commentary, “Time Frame of Preferences, Dispositions, and Advance Directives,” *Philosophy, Psychiatry & Psychology*, 5:247-49, 1998.

“Institutional Animal Care and Use Committees,” in *Encyclopedia of Animal Rights and Animal Welfare*, M. Bekoff, ed., Westport, Connecticut: Greenwood Press, 1998, 2d ed. 2010.

“‘Innovative’ Surgery Was an Experiment in Disguise,” *New York Times*, June 23, 1998, at A18 (letter).

Commentary, “An Alert and Incompetent Self: The Irrelevance of Advance Directives,” *Hastings Center Report*, 28:28-29, Jan.-Feb. 1998.

“Nervous Doctors,” *New York Times*, November 24, 1997, at A16 (letter).

“The Rule of Double Effect,” *New England Journal of Medicine*, 338:1390, 1998 (reply to correspondence). Co-authored with Timothy Quill, M.D. and Dan Brock, Ph.D.

"Emergency Research and Research Involving Subjects with Cognitive Impairment: Ethical Connections and Contrasts," *Journal of the American Geriatrics Society*, 45:521-523, 1997 (editorial). Co-authored with Peter Whitehouse, M.D., Ph.D.

"Ethics of Proxy Consent for Research Involving Patients with Adult Respiratory Syndrome," *Journal of the American Medical Association*, 276:949-50, 1996 (letter).

Committee on Drugs and Committee on Bioethics, "Considerations Related to the Use of Recombinant Human Growth Hormone in Children," *Pediatrics*, 99:122-129, 1997 (primary ethics author).

"Delegating the Notification of Death" and "Conscientious Objections," in *Ethics in Emergency Medicine* 262-65, 267-270, K. Iserson, A. Sanders & D. Mathieu, eds., Tucson: Galen Press, 2d ed. 1995 (case commentaries).

"Conscientious Objections" reprinted in P. Windt & L. Francis, eds., *Ethical Issues in the Professions*, Prentice-Hall, 1989.

"Baboon-to-Human Transplants: Should We Proceed?" *Making the Rounds*, 1:1, 3, October 9, 1995. Co-authored with Robert M. Arnold, M.D.

"Problems in Law and Bioethics: Introduction," *Health Matrix: Journal of Law-Medicine*, 5:ix, Summer 1995.

"Confronting the 'Near Irrelevance' of Advance Directives," *Journal of Clinical Ethics*, 5:55-56, 1994 (editorial).

Committee on Bioethics, American Academy of Pediatrics, "Infants with Anencephaly as Organ Sources: Ethical Considerations," *Pediatrics*, 89:1116-19, 1992 (primary author).

"Sources of Concern about the Patient Self-Determination Act," *New England Journal of Medicine*, 325:1666-71 (1991) (one of many authors).

"Bioethicists' Statement on U.S. Supreme Court's *Cruzan* Decision," *New England Journal of Medicine*, 323:686-87 (1990) (one of many authors).

Book Review, *World Health Organization International Digest of Health Legislation*, 1990 (reviewing Weir, *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life*, 1989).

Collaborator, "Animals in Science: The Justification Issue," in "Animals, Science and Ethics," Special Supplement, *Hastings Center Report*, May/June 1990.

"The Legal Context of Palliative Care," in *Decisions at the End of Life*, Center for Health Promotion and Education, Newton, Massachusetts: Education Development Center, 1989 (continuing education materials for health care professionals).

"Death with Dignity: Patients' Rights and the Texas Hospice Movement," *Personal Choices and Public Commitments* 81-92, W. Winslade, ed., Galveston, Texas: Institute for the Medical Humanities, 1988 (monograph).

"Physician Risk Preferences and Patient Care," *Chest*, 93:674-75, 1988 (editorial). Co-authored with Eugene V. Boisaubin, Jr., M.D.

Book Review, *Jurimetrics Journal*, 28:251-254, 1987 (reviewing Appelbaum, Lidz & Meisel, *Informed Consent: Legal Theory and Clinical Practice*, 1987).

"Refining the Review Committee Process: Policies and Procedures," in *Scientists' Center for Animal Welfare Newsletter*, 9(1):3-5, Spring 1987.

"The Case for the Use of Animals in Biomedical Research," *New England Journal of Medicine*, 316:552, 1987 (letter).

"Regulation of Animal Experimentation," *Journal of the American Medical Association*, 255:1567-68, 1986 (letter).

Book Review, "The DES Disaster and Other Hazards," *Hastings Center Report*, 15:46-47, October 1985 (reviewing Apfel & Fisher, *To Do No Harm: DES and the Dilemmas of Modern Medicine*, 1984).

"Obligatory Running and Anorexia Nervosa," *Journal of the American Medical Association*, 253:979-80, 1985 (letter).

Book Review, *Journal of Medicine and Philosophy*, 9:423-25, 1984 (reviewing Dodds & Orlans, eds., *Scientific Perspectives on Animal Welfare*, 1982).

"Involuntary Confinement: Legal and Psychiatric Perspectives," *Journal of Medicine and Philosophy*, 9:295-99, 1984 (commentary on J. Callahan, "Liberty, Beneficence, and Involuntary Confinement," same issue).

"On Weinstein's 'Patient Attitudes toward Mental Hospitalization: A Review of Quantitative Research,'" *Journal of Health and Social Behavior*, 21:393-96, 1980 (co-authored with others in postdoctoral fellowship program).

#### GRANTS AND CONTRACTS

Consultant, "HIV Cure Studies: Risk, Risk Perception, and Ethics," National Institutes of Health, National Institute of Allergy and Infectious Diseases, 1R01 AI114617, 2015-2019.

Co-Investigator, "Communication Preferences for Genome Sequencing Among Young Breast Cancer Patients," National Cancer Institute, National Institutes of Health, 1R01 CA16860801, 2012-2015.

Washington University Clinical and Translational Sciences Award, National Institutes of Health, Clinical Research Ethics Subproject, UL1 TR000448, 2007-15.

Principal Investigator, "Bioethics and Cancer: When the Professional Becomes Personal," Greenwall Foundation, 2008.

Principal Investigator, "Germ-Line Interventions and Human Research Ethics," National Human Genome Research Institute, National Institutes of Health Grant Number 1 R01 HG02493-01, 2002-2005.

Core Research Team, "Pediatric Research Ethics: A Multidisciplinary Analysis," Greenwall Foundation, 2001-2002.

Commissioned Paper for National Academy of Sciences Panel on Risk and Prevalence of Elder Abuse and Neglect, "Ethical and Policy Issues in Research on Elder Abuse and Neglect," 2001.

"Advance Directives in Dementia Research: Promoting Autonomy and Protecting Subjects," Borchard Foundation Center on Law & Aging, 1999-2000.

Project Consultant, "Therapeutic Research Consent: Empirical and Ethical Analysis," Program on Informed Consent in Research Involving Human Participants, National Institutes of Health, 1997-2000.

Commissioned Paper for National Bioethics Advisory Commission, "Research Involving Persons With Mental Disabilities: A Review of Policy Issues and Proposals," August, 1997.

Project Consultant, "The Use of Animals in Psychological Research: A National Study of Institutional Animal Care



and Use Committees," Ethics and Values Studies Program, National Science Foundation, 1997-99.

Senior Consultant, "Testing the Effectiveness of Advance Medical Directives," Agency for Health Care Policy and Research, U.S. Public Health Service, 1995-99.

Principal Investigator, "Ethical Review Standards and Procedures for Scientific Research Using Animals," Cross-Disciplinary Study Award, Ethics and Values Studies Program, National Science Foundation, 1986-88.

"Legal and Ethical Issues in Patenting New Animal Life," Greyhound Fellowship Award, Center for the Study of Law, Science and Technology, College of Law, Arizona State University, 1987-88.

### PROFESSIONAL ACTIVITIES

Contributing Editor and Editorial Board Member, *Hastings Center Report*, 2016-present.

Editorial Board, *IRB: Ethics & Human Research*, 2000-present.

"At Law" columnist, *Hastings Center Report*, 1996-present.

Editorial Board, *Narrative Inquiry in Bioethics*, 2017-present.

Editorial Board, *Journal of Law & the Biosciences*, 2012-present.

Advisory Board, *International Journal of Feminist Approaches to Bioethics*, 2009-present.

Gene and Cell Therapy Data Safety and Monitoring Board, National Heart, Lung, and Blood Institute, National Institutes of Health, 2017-present.

Hastings Center Board of Directors and Fellows Council Chair, 2014-2016, Vice-Chair 2012-2014.

National Institutes of Health Recombinant DNA Advisory Committee, 2011-2015.

Affiliated Faculty, Washington University Department of Philosophy, Spring 2013-17.

Institute Scholar, Washington University Institute of Public Health, Spring 2013-17.

Invited Participant, Drawing the Line: Ethical, Policy and Scientific Perspectives on U.S. Embryo Research Conference, Rice University, May 23-24, 2018.

Guest Faculty, National Institutes of Health Fogarty International Center Training Program in Research Ethics in the Americas, Buenos Aires, Argentina, May 8-12, 2017.

Best Practices Working Group for Institutional Review Board Review of Disaster and Emergency Related Public Health Research, National Institute of Environmental Health Sciences, 2016.

Board of Scientific Counselors, National Institutes of Health, Bioethics Department Review, January 5-6, 2015.

John and Marsha Ryan Bioethicist-in-Residence, Southern Illinois University, March 28-30, 2012.

National Human Genome Research Institute Special Emphasis Panel, November 13, 2012.

Working Group, Nanodiagnostics and Nanotherapeutics: Building Research Ethics and Oversight, University of

Minnesota, 2009-2011.

President's Council on Bioethics, 2002-2009.

Invited Participant, "Contending Modernities," Notre Dame Centre, London, July 8-10, 2011.

Board of Scientific Counselors, National Institutes of Health, Bioethics Department Review, January 25, 2011.

Project Participant, "Human Subjects Protections in Community-Based Participatory Research," National Institutes of Health Clinical and Translational Science Award, University of Chicago, 2009.

Working Group, "The Ethical and Policy Implications of Attenuating Growth in Children with Profound Developmental Disabilities," University of Washington, 2008.

Invited participant, Centre for Research on Personhood in Dementia Workshop, University of British Columbia, Vancouver, May 14-15, 2007.

Invited Participant and Commentator, "Rethinking Health Law," Wake Forest University Law School, December 9-10, 2005.

Hastings Center Fellows Nominating Committee, 2005.

Merck Visiting Scholar, Seton Hall University School of Law, March 7-11, 2005.

Program Committee, "Health Advocates in Research: A Participatory Conference," Sarah Lawrence College, 2004-2005.

Editorial Board, *American Journal of Bioethics*, 2000-2004.

Reviewer, American Society for Bioethics and Humanities Annual Meeting Program Committee, 2004.

Invited Participant, Lasker Foundation Forum on Ethical Challenges in Biomedical Research and Practice, Washington, DC, May 14-16, 2003.

Participant, Hastings Center Project on Conflicts of Interest in Health and Medical Research, 2002-2003.

Invited Participant and Speaker, Texas Law Review Symposium on Precommitment Theory, Bioethics, and Constitutional Law, Austin, Texas, September 20-21, 2002.

Invited Participant, National Human Genome Research Institute Planning Workshop on Bioethics and Humanities Research, Bethesda, Maryland, July 2, 2002.

Member, National Institute of Mental Health Special Emphasis Panel, Washington, DC, June 19, 2002.

Member, Advisory Council, National Institute on Deafness and Other Communication Disorders, National Institutes of Health, 1997-2001. Member, NIDCD Ad Hoc Working Group on Public Liaison.

Member, Planning Committee, "Making Informed Consent Meaningful," Veterans Administration State of the Art Conference, 2000-2001.

Invited Participant and Commissioned Paper Author, Joint Conference on Legal & Ethical Issues in the Progression of Dementia, University of Georgia, November 30-December 2, 2000.

Invited Participant, American Association for the Advancement of Science-National Institutes of Health Office for Protection from Research Risks Workshop on Ethical and Legal Aspects of Human Subjects Research in Cyberspace, June 10-11, 1999.

Research Ethics Consultant, John F. Kennedy Center for Research on Human Development, Vanderbilt University, April 27, 1999.

Member, Annual Meeting Program Committee, American Society for Bioethics and Humanities, 1999.

Member, Ad Hoc Study Section, "Ethical, Legal and Social Implications of Human Genetics Research," National Institutes of Health, Washington, December 7-8, 1998.

Member, Advisory Work Group on Human Subject Research, New York State Department of Health, 1997-1998.

Ethics Committee, American Society for Reproductive Medicine, 1997-2002.

Member, Washington University Medical Center Institutional Review Board, 1998-2015.

Member, Washington University Medical Center Embryonic Stem Cell Research Oversight Committee, 2007-2015.

Member, Washington University Alzheimer's Disease Research Center Ethics Committee, 2007-present.

Member, Ethics Committee, University Hospitals of Cleveland, 1993-98.

Member, Ethics Committee, MacDonald Hospital for Women, Cleveland, 1990-98.

Member, Institutional Animal Care and Use Committee, Case Western Reserve University, 1990-98.

Invited Reviewer, National Bioethics Advisory Commission Draft Report, "Research Involving Subjects with Disorders That May Affect Decision-Making Capacity," July, 1998.

Program Chair, Tenth Annual Bioethics Summer Retreat, Cape Cod, June 17-21, 1998.

"Breakfast with an Author," Annual Meeting, Association of Practical and Professional Ethics, Dallas, Texas, Feb. 27, 1998.

Co-Chair, Symposium on Informed Consent in Clinical Trials, 13th International Conference, Alzheimer's Disease International, Helsinki, September 30, 1997.

Moderator, "Institutional Experiences in Protecting Complainants and Respondents," U.S. Department of Health and Human Services Office of Research Integrity Workshop for Institutional Misconduct Officials, Washington, June 7, 1997.

Fellowship Program Review Committee, Bioethics Institute, Johns Hopkins University, Baltimore, May 17, 1997.

Member, Special Emphasis Panel, National Institute of Mental Health Initial Review Group, Washington, March 14, 1997.

Participant, "Challenges to Choice: Reexamining the Ethics of End-of-Life Care," Hastings Center, New York, January 25, 1997.

Review Committee Member, Harvard Medical School Medical Ethics Program, Boston, April 4, 1996.

Participant, Conference on Sociology of Medical Ethics, University of Michigan Law School, September 15-17, 1995.

Planning Committee, Project on Defining Death in a Technological Age, University Hospitals of Cleveland, Case Western Reserve University, and Institute of Medicine, National Academy of Sciences, 1994-1995.

Participant, Meeting of Working Group on Informed Consent in Clinical Research Conducted Under Emergent Circumstances, National Institutes of Health, Bethesda, Maryland, July 27, 1994.

Member, Conflict of Interest Committee, School of Medicine, Case Western Reserve University, 1994-95.

Participant and presenter, Advance Directives: Conference on Research Methods and Priorities, Holderness, New Hampshire, September 9-12, 1993.

Core Research Group, Hastings Center Project on Long-Term Contraception, 1992-93.

Participant, "Liberty, Risk, and Human Rationality," Liberty Fund Conference, Williamsburg, Virginia, October, 1992.

Co-chair, Strategy Development Session on Harassment, Workshop on Women in Biomedical Careers, National Institutes of Health Office of Research on Women's Health, Bethesda, Maryland, June, 1992.

Core Research Group, Hastings Center Project on the Patient Self-Determination Act, 1991.

Core Research Group, Hastings Center Project on Feminism and Bioethics, 1991.

Initial Review Group, Ethical, Legal and Social Implications Program, National Center for Human Genome Research, National Institutes of Health, Bethesda, Maryland, April 1-3, 1991.

Officer, Section on Law and Mental Disability, Association of American Law Schools, 1991-94.

Planning Committee for Health Law Teachers Conference, American Society of Law and Medicine, 1989-90.

Planning Committee for Health, Law and Aging Conference, Case Western Reserve University Center on Aging and Health, 1989-1990.

Core Research Group, Hastings Center Project on Ethics of Animal Research, 1988-1990.

Member, Animal Care Committee Guidebook Editorial Board, 1988-1992.

Legal Consultant, Committee on Bioethics, American Academy of Pediatrics, 1987-1994.

Member, Chimpanzee Breeding and Research Program Advisory Committee, National Institutes of Health, 1987-92.

Member, Advisory Board, *Journal of Medicine and Philosophy*, 1984-1992.

Member, National Advisory Board, *BioLaw: A Legal and Ethical Reporter on Medicine, Health Care, and Bioengineering*, 1986-90.

Member, Alumnae Committee, Harvard Law School Association, 1985-1988 and Steering Committee, Celebration 35, 1987-88.

Member, Health Law Institute Advisory Board, University of Houston Law Center, 1986-1988.

Member, Animal Research Committee, Baylor College of Medicine, 1985-1988.

Member, Animal Welfare Committee, University of Texas Health Science Center at Houston, 1985-1988.

Member, Animal Studies Subcommittee, Veteran's Administration Medical Center at Houston, 1985-1988.

Member, Committee on Continuing Education, Baylor College of Medicine, 1984-1988.

Member, Committee for the Protection of Human Subjects, University of Wisconsin Health Sciences Center, 1980-1981.

Volunteer Attorney in Mental Health Law, Center for Public Representation, Madison, Wisconsin, 1979-1980.

Manuscript Reviews, *Science*, *New England Journal of Medicine*, *American Journal of Public Health*, *Milbank Quarterly*, *JAMA*, *Journal of Law, Medicine & Ethics*, *Journal of Clinical Ethics*, *Kennedy Institute of Ethics Journal*, *Social Science and Medicine*, *Annals of Internal Medicine*, *Archives of Internal Medicine*, *Hastings Center Report*, *IRB: Ethics and Human Research*; *Journal of Medicine and Philosophy*, *Pediatrics*, *Journal of the Society for Clinical Trials*, *PLoS Medicine*, *Nature Reviews Genetics*, *Journal of Medical Ethics*, *Journal of Genetic Counseling*, *Theoretical Medicine and Bioethics*, *Cancer*, Institute of Medicine, National Science Foundation, Johns Hopkins University Press, Oxford University Press.

## HONORS

2014 Washington University Distinguished Faculty Award

2014 Women's Justice Award, St. Louis Lawyers Weekly

Hastings Center Fellow

Phi Beta Kappa

Alpha Lambda Delta (women's honorary)

Indiana University Merit Scholarships

## PRESENTATIONS

"Dementia, Disability, and Advance Medical Directives: Toward a Defensible Legal Framework for Individual Decisions about Future Dementia Care," Beyond Disadvantage: Disability, Law, and Bioethics, Harvard Law School, June 1, 2018.

"What Research Participants Can Teach Us about Research Ethics," Koo Foundation Sun Yat-Sen Cancer Center, May 14, 2018.

"Research Ethics and Regulation: Recent Developments in Research Ethics and US Research Regulation," 2018 Conference on Research Ethics and National Bioethics Committees, National Taiwan University Hospital, May 11, 2018.

"National Bioethics Commissions: Issues and Objectives," 2018 Conference on Research Ethics and National Bioethics Committees, National Taiwan University Hospital, May 11, 2018.

"Ethical Issues in Biobank Research: Informed Consent, Return of Results, and Payment to Donors," National Chiao Tung University, Taiwan, May 10, 2018.

“Ethical (and Policy) Issues in Human Gene Editing Research,” National Chiao Tung University, Taiwan, May 10, 2018.

Panelist, Public Workshop: Evaluating Inclusion and Exclusion Criteria in Clinical Trials, FDA/Duke Margolis Center for Health Policy, National Press Club, Washington, DC, April 16, 2018.

Discussant, “Who Should Apologize for Medical Errors?” Ethics Grand Rounds, National Institutes of Health December 6, 2017.

“The Hidden World of Subjects: Rule-Breaking in Clinical Trials,” Inter-Institute Bioethics Interest Group, National Institutes of Health, December 4, 2017.

“Patient Advocates in Clinical Research,” Fall Speaker Form, Wisconsin Breast Cancer Coalition, Milwaukee, Wisconsin, November 10, 2017.

“Who Is the Reasonable Subject?” Panel on Making Consent Meaningful in the Context of the Revised Common Rule, PRIM&R Advancing Ethical Research Conference, November 8, 2017, San Antonio..

Keynote, “What We Can Learn about Research Ethics from Experienced Subjects,” Bioethics Research Day, Cleveland Clinic, November 6, 2017.

“Should the Law Permit Assisted Death for Dementia?” American Society for Bioethics and Humanities Annual Meeting, Kansas City, Missouri, October 20, 2017.

“Should the Law Permit Physician-Assisted Death for Dementia?” Health Law Policy & Ethics Seminar, University of Toronto Law School, Toronto, Canada, October 12, 2017.

“What We Can Learn about Research Ethics from Experienced Subjects,” Ethical and Regulatory Aspects of Clinical Research Course, National Institutes of Health, Bethesda, Maryland, September 27, 2017.

Panelist, “Ethics and Patient Advocacy in Clinical Trial Design,” New York Academy of Sciences, The Need to Accelerate Therapeutic Development — Must Randomized Controlled Trials Give Way? New York City, June 21, 2017.

“Silent Partners,” Contemporary Books in Bioethics Public Forum and Course Discussion, Harvard Medical School, Boston, April 20-21, 2017.

“What Patients and Subjects Say about Research Participation,” Canadian Health Ethics Week Presentation, McGill University Health Centre, Montreal, April 3, 2017.

“Patient Perspectives on Breaking Bad News and Treatment Decision Making,” Student Lecture, Western Michigan University School of Medicine, March 23, 2017.

“Does Everyone Have a Duty to Volunteer for Research?” Medical Ethics, Humanities & Law Grand Rounds, Western Michigan University School of Medicine, March 22, 2017.

“The Choice to Become a Research Subject: A First-Person Perspective,” Bioethics Brownbag & Webinar Series, Michigan State University Center for Ethics and Humanities in the Life Sciences, March 22, 2017.

Author Meets the Commentators Session, Association for Practical and Professional Ethics Annual Meeting, Dallas, Texas, February 25, 2017.

Panelist, “Reflections from the Nation’s Capital: Looking to the Future of National Bioethics Advisory Bodies,” Annual Meeting, American Society for Bioethics and Humanities, Washington, DC, October 7, 2016.

“Why Experienced Subjects Belong in Research Ethics,” Annual Meeting, American Society for Bioethics and Humanities, Washington, DC, October 6, 2016.

“Ethical Issues in Gene Transfer Research: Past, Present, Future,” Office of Clinical Research Policy and Regulatory Operations, National Institute of Allergy and Infectious Diseases, Bethesda, September 20, 2016.

“Exploratory Trials in Vulnerable Populations,” Workshop on Therapeutic Development for Nervous System Disorders in the Absence of Predictive Models of Disease, National Academy of Sciences, Washington, DC, September 13, 2016.

Panelist, “Reflecting on the Past, Present, and Future Impact of National Bioethics Advisory Bodies,” Presidential Commission for the Study of Bioethical Issues, Philadelphia, August 31, 2016.

“Bioethics and Cancer: When the Professional Becomes Personal,” Public Lecture, Oregon State University, April 18, 2016.

“Complexity in Treatment Decision Making,” Benton Hospice Service, Corvallis, Oregon, April 18, 2016.

“When Patients Make ‘Bad’ Choices,” Ethics Center Lecture Series, UCLA Health System, Los Angeles, February 17, 2016.

“Literary Research Ethics,” Annual Meeting, American Society for Bioethics and Humanities, Houston, October 16, 2015.

“Risks, Benefits, and Ethics in Gain-of-Function Studies,” The Ethical, Legal, and Policy Issues Associated with Gain-of-Function Studies, National Science Advisory Board for Biosecurity, National Institutes of Health, September 28, 2015.

“Patient Advocacy and Biomedical Research Funding,” American Society of Gene & Cell Therapy Annual Meeting, New Orleans, May 14, 2015.

“Making Studies Less Risky: Lessons from First-in-Human Studies,” HIV Cure Studies: Risk, Risk Perception, and Ethics Workshop, Harvard Medical School, Boston, May 8, 2015.

Speaker, “Designing an Ethically Acceptable Investigation of MRT in the United States,” Workshop on Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial Diseases, Institute of Medicine, Washington, DC, March 1, 2015.

“The ‘Right to Try’ Investigational Drugs: Science and Stories in the Access Debate,” Symposium on Science Challenges for Law and Policy, University of Texas Law Review, Austin, January 30, 2015.

Speaker, “Methodology for Evaluating the Degree of Risk and Determining Risks That Are Reasonably Foreseeable,” Workshop on Ethical Review and Oversight in Research Involving Standard of Care Interventions,” Institute of Medicine, Washington, DC, December 2, 2014.

“The Hidden Lives of Subjects: Rule-Breaking and Ethics,” Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Baltimore, Dec. 7, 2014.

“What Subjects Teach: The Everyday Ethics of Human Research,” Symposium on Relationship-Centered Health Care: Implications for Law and Ethics, Wake Forest University Law Review, Winston-Salem, North Carolina, October 24, 2014.

“Inclusive Research Ethics,” Annual Meeting, American Society for Bioethics and Humanities, San Diego, October 16, 2014.

“Research Involving Decisionally Impaired Persons,” Neuroscience Across Life Stages, Presidential Commission for the Study of Bioethical Issues, Atlanta, June 9, 2014.

“Ethicists Confront Cancer: When the Professional Becomes Personal,” Community Forum, Center for Ethics in Science & Technology, San Diego, June 4, 2014.

“A Fate Worse Than Death? How Biomarkers for Alzheimer’s Disease Could Affect End-of-Life Choices,” Indiana Health Law Review Symposium, Indiana University School of Law, Indianapolis, March 28, 2014.

Panelist, “Gene Patenting,” Annual Symposium, Journal of Technology & Intellectual Property, Northwestern University School of Law, February 28, 2014.

“Taking Subjects Seriously: A New Look at Research Ethics,” Law and Biosciences Workshop, Stanford Law School, January 28, 2014.

“Ethics of Clinical Trials in the Genomic Era,” Symposium on Clinical Trial Design in the Era of Genomic Medicine, Research Advocacy Network, Dallas, November 22, 2013.

“Subversive Subjects: Rule-Breaking and Deception in Clinical Trials,” American Society for Bioethics and Humanities Annual Meeting, Atlanta, October 26, 2013.

Plenary Session, “A Tribute to Edmund Pellegrino and His Work,” American Society for Bioethics and Humanities Annual Meeting, Atlanta, October 24, 2013.

“Patients’ Perspectives on Cancer Ethics,” Fairbanks Ethics Lecture, Indiana University Health, Indianapolis, September 4, 2013.

“Clinical Ethics,” Institute of Medicine Committee on Approaching Death: Addressing Key End-of-Life Issues, Baylor College of Medicine, Houston, Texas, July 22, 2013.

“Cancer Ethics: The Teachings of Personal Experience,” Keynote Address, Intensive Workshop in Health Care Ethics, University of Arkansas College of Medicine, Little Rock, May 3, 2013.

“When Doctors Should Argue with Patients,” Arkansas Medical Society Distinguished Lecturer, University of Arkansas College of Medicine, Little Rock, May 2, 2013.

“Paternalism vs. Partnership in Genetic Research,” Annual Conference, Association for the Accreditation of Human Research Protection Programs, Miami Florida, April 5, 2013.

“Biomedical and Behavioral Research in Chimpanzees – Should There Be Differences in Criteria for Moral Justification?” Kennedy Institute of Ethics, Georgetown University, Washington, DC, May 3, 2012.

“Does Everyone Have a Duty to Participate in Research?” Southern Illinois University School of Medicine, Springfield, Illinois, March 30, 2012.

“Advance Directives and the ‘Changing Selves’ Problem,” Memorial Hospital, Carbondale, Illinois, March 29, 2012



and St. John's Hospital Medical Morals Committee, Springfield, Illinois, March 30, 2012.

Public Lecture, "When Seriously Ill Patients Make Bad Choices," Southern Illinois University School of Law, Carbondale, Illinois, March 28, 2012.

"Ethical Issues in Research and Early Development of Nutritional Nanotechnology," Joint NIH and USDA Workshop on Using Nanotechnology to Improve Nutrition Through Enhanced Bioavailability and Efficacy," Bethesda, Maryland, November 30, 2011.

"Alive and Well: The Research Imperative," Research Ethics: Re-Examining Key Concerns, Wake Forest University, Winston-Salem, North Carolina, November 11, 2011.

"Building an Ethical Foundation for First-in-Human Nanotrials," Nanodiagnostics and Nanotherapeutics: Building Research Ethics & Oversight," University of Minnesota, Minneapolis, September 26, 2011.

Panelist, "U.S. Bioethics Commissions: Several Generations and Multiple Transformations," American Society for Bioethics and Humanities Annual Meeting, Minneapolis, Minnesota, October 15, 2011.

Commentator, "In Their Own Voices: A Discussion with Research Subjects Who Also Work in the Field of Subject Protections," Advancing Ethical Research Conference, Public Responsibility in Medicine and Research, San Diego California, December 7, 2010.

Participant, "Great Debate: The Obligation to Participate in Research," Advancing Ethical Research Conference, Public Responsibility in Medicine and Research, San Diego California, December 8, 2010.

Panelist, "Human Dignity and the Practice of Medicine: Conceptual, Empirical, and Clinical Challenges in Operationalizing a Contested Concept," American Society for Bioethics and Humanities Annual Meeting, San Diego, California, October 22, 2010.

Panelist, "Nanomedicine Research Ethics: Beyond Research Participants to the Community," American Society for Bioethics and Humanities Annual Meeting, San Diego, California, October 22, 2010.

"When Patients Make Bad Choices: Autonomy and Persuasion in Treatment Decision-Making," Annual Health Ethics Conference, University of Missouri School of Medicine, Columbia, Missouri, October 8, 2010.

"Policy and Strategy," Tarrytown Meeting on New Human Biotechnologies, Tarrytown, New York, July 29, 2010.

"Decisions about Cancer Treatment: A Personal Perspective on Autonomous Choice," Annual Health Law Professors Conference, University of Texas Law School, Austin, June 4, 2010.

"Ethics of Animal Research," Animal Research Roundtable, Kingenstein Fund, New York, April 20, 2010.

"Perfect Children: Designer Babies and Research Ethics," Ethics and Human Enhancement Symposium, University of North Carolina, Chapel Hill, April 13, 2010.

"Avoiding the Conscientious Objection 'Emergency,'" Symposium on The Future of Rights of Conscience in Health Care, Brigham Young University Law School, Provo, Utah, February 26, 2010.

"First-in-Human Research Challenges," Nanodiagnostics and Nanotherapeutics: Building Research Ethics and Oversight, University of Minnesota, January 21, 2010.

"Bioethics and Aging," A New Look at Old Age: Cross-Disciplinary Perspectives on Law and Aging, Association of American Law Schools Annual Meeting, New Orleans, January 9, 2010.

“End-of-Life Decisions after the *Schiavo* Case,” University of North Texas Health Science Center and JPS Health Network, Ft. Worth, Texas, November 11 and November 12, 2009.

Panelist and Moderator, “Bioethics and Cancer: When the Professional Becomes Personal,” American Society for Bioethics and Humanities Annual Meeting, Washington DC, October 16, 2009.

Panelist, “Severe Brain Injury and Sexuality,” American Society for Bioethics and Humanities Annual Meeting, Washington DC, October 15, 2009.

“Advance Directives and the ‘Changing Selves’ Problem,” Medical Humanities Conference, University of Rochester School of Medicine, October 7, 2009.

“Life-Sustaining Treatment for Dementia Patients,” Monroe County Hospital Geriatrics Grand Rounds, Rochester, New York, October 7, 2009.

“Stem Cell Research: Expanding the Ethical Conversation,” Public Lecture, University of Rochester School of Medicine, October 6, 2009.

“Dignity Can Be a Useful Concept in Bioethics,” Nursing and Social Work Grand Rounds, University of Rochester School of Medicine, October 6, 2009.

“When Patients Make Questionable Choices: Autonomy and Persuasion in Treatment Decision-Making,” Medicine Grand Rounds, University of Rochester School of Medicine, October 6, 2009.

Panelist, “Bioethics and Politics,” The Hastings Center 40<sup>th</sup> Anniversary Celebration, New York City, June 12, 2009.

Panelist, “Social and Health Policy Issues,” Law & Innovation: The Embryonic Stem Cell Controversy, University of Texas School of Law, Austin, May 2, 2009.

“Human Nature and Human Dignity,” Bioethics, Public Moral Argument, and Social Responsibility Conference, Wake Forest University, Winston-Salem, North Carolina, April 27, 2009.

“The Therapeutic Misconception,” Issues in Medical Ethics 2009, Mt. Sinai School of Medicine, New York, March 6, 2009.

“Patient Advocates in Research,” Innovation and Integration: The Future of Research Subject Advocacy, Society of Research Subject Advocates Web Conference, December 11, 2008.

Panelist, “Voice and Empathy,” Cancer Stories: The Impact of Narrative on a Modern Malady, Indiana University-Purdue University, Indianapolis, Indiana, November 7, 2008.

Panelist, “Outside the OR—Economic, Regulatory, and Legal Challenges,” Ethical Challenges in Surgical Innovation, Cleveland Clinic, May 9, 2008.

“Stem Cell Research: The Diversity of Ethical Issues,” Keynote Speech, Center for Law, Society and Culture Symposium, Indiana University, Bloomington, Indiana, March 27, 2008.

Ethics Across the Curriculum Lecture, Public Affairs Convocation Series, Missouri State University, Springfield, Missouri, March 12, 2008.

“The Law and Ethics of Off-Label Prescribing, Faculty Workshop, Arizona State University College of Law, February 13, 2008.

“What Counts as Success in Public Bioethics Commissions?” Meeting on Reassessing National Bioethics Commissions in the United States, University of Pennsylvania, Philadelphia, December 7, 2007.

Commentator, “The State’s Interest: The Implications of *Gonzales v. Carhart* and Other Recent Cases,” George Washington University Law Review Symposium, Washington, DC, November 2, 2007.

Panelist, “Treatment Refusal or Assisted Suicide? Forgoing Life Support in the Immediate Aftermath of a Suicide Attempt,” American Society for Bioethics and Humanities Annual Meeting, Washington, DC, October 20, 2007.

“Patient Advocates in Research: New Possibilities, New Problems,” Brown University Medical School, Providence, September 25, 2007.

“Stem Cell Research: The Diversity of Ethical Issues,” Brown University Graduate School Academy in Context, Providence, September 25, 2007.

“The Ethical and Policy Implications of Stem Cell Research,” Judicial Conference, Second Judicial Circuit of the United States, Bolton Landing, New York, June 8, 2007.

“Decision-Making, Capacity, and Dementia,” Centre for Research on Personhood in Dementia Colloquium, University of British Columbia, Vancouver, May 16, 2007.

“Terri Schiavo and Contemporary Myths about Dying,” Matthew Vandivier Sims Memorial Lecture, Poynter Center for the Study of Ethics and American Institutions, Indiana University-Bloomington, March 1, 2007.

Panelist, “The Chimeric Human Application and What Comes Next?” Patenting People, Cardozo School of Law, New York, November 12, 2006.

“End-of-Life Decisions after *Schiavo*,” California Western School of Law, San Diego, February 10, 2006.

Panelist, “Human Embryonic Stem Cell Research: The Promises, the Perils, and the Politics,” Association of American Law Schools Annual Meeting, Washington, DC, January 5, 2006.

“Private-Sector Research Ethics,” Faculty Colloquium, Notre Dame Law School, November 11, 2005.

“Autonomy is Not the Answer: Rewriting the Law on Life-Sustaining Treatment for Dementia Patients,” P. Browning Hoffman Memorial Lecture in Law and Psychiatry, University of Virginia, Charlottesville, October 11, 2005.

“Ethics in Human Embryonic Stem Cell Research,” Bioethics Symposium, School of Christian Studies, San Diego, October 8, 2005.

“Ethics in Pharmaceutical Research,” Faculty Workshop, Case Western Reserve University Law School, Cleveland, September 28, 2005.

“Patient Advocates in Clinical Research,” Cleveland Clinic, September 27, 2005.

“Designing Babies: Human Research Issues,” Conversations in Bioethics, Case Western Reserve University School of Medicine, Cleveland, September 27, 2005.

“Stem Cell Research: Problems with the Public Debate,” Collegium da Vinci Symposium, Southern Methodist

University, Dallas, September 17, 2005.

Panelist, “Stem Cell Research: Legislative Update—Who Will Control the Future of Medicine?” Section of Science and Technology Law, American Bar Association Annual Meeting, Chicago, August 6, 2005.

“Anticipating an Ethical Dilemma: Designer Genes,” Congressional Biomedical Research Caucus Briefing, Rayburn House Office Building, Washington, DC, July 27, 2005.

“Private-Sector Research Ethics,” 14<sup>th</sup> Annual Conley Ethics Lecture, St. Vincent’s Hospital, New York, June 10, 2005.

“Ethical Perspectives on Moral Agency and Free Will,” Our Brains and Us: Neuroethics, Responsibility and the Self, Massachusetts Institute of Technology, April 19, 2005.

“Life-Sustaining Treatment for Incompetent Patients: Beyond Advance Directives,” St. Luke’s Hospital Annual Ethics Conference, Chesterfield, Missouri, April 7, 2005.

“Futile Science? Designer Babies as a Research Aim,” Faculty Colloquium, Seton Hall Law School, March 11, 2005.

“Stem Cell Research: The Bigger Picture,” Seton Hall Law School, Newark, New Jersey, March 10, 2005.

Plenary Panel, “Ethics of Research in Advocacy,” Health Advocates in Research: A Participatory Conference, Sarah Lawrence College, New York, January 14, 2005.

“Federal Oversight,” Babies by Design: Policy Options for Human Germline Genetic Modification,” Genetics & Public Policy Center, Washington, DC, December 16, 2004.

“Bioethics and Conflicts of Interest,” University of Tokyo Symposium on Conflicts of Interest in the Legal and Medical Professions, Tokyo, Japan, December 4, 2004.

Ethics Panel, “Stem Cells: Saving Lives or Crossing Lines?” Rice University, Houston, November 20, 2004.

Panel, “Hope in Clinical Trials,” Annual Meeting, American Society for Bioethics and Humanities, October 30, 2004.

“Stem Cell Research: The Big Picture,” Conley Lecture, SUNY Downstate Medical Center, Brooklyn, October 5, 2004.

“Stem Cell Research and the Public Imagination,” The Stem Cell Debate in the United States and the Federal Republic of Germany,” Catholic University, Washington, DC, October 4, 2004.

“The Work of the President’s Council on Bioethics,” Special Committee on Bioethics and the Law, American Bar Association, Atlanta, August 7, 2004.

“Designing Humans: Research Ethics Issues,” Ethics Grand Rounds, University of Texas Southwestern Medical Center, Dallas, May 11, 2004.

“The Consumer’s Role in Contemporary Medicine,” Ackerman Symposium on Professional Values in the Age of Consumer Medicine, Harvard Medical School, Boston, April 23, 2004.

“The Wisdom of Advance Directives,” President’s Council on Bioethics, Washington, DC, April 2, 2004.

“Patient Advocates and Research: Exploring Ethical and Policy Issues,” Children’s Oncology Group Spring Meeting, Washington, DC, March 31, 2004.

“When Science Offers Salvation: Advocacy’s Impact on Research Ethics, Policy, and Law,” Fordham University Ethics Center Fellows Lecture, New York, March 9, 2004.

“Human Embryonic Stem Cell Research: Expanding the Ethical Analysis,” Drummond Lecture, Center for Health Care Ethics, St. Louis University, March 5, 2004.

“The Ethics of PGD,” Unnatural Selection: Should California Regulate Pre-Implantation Genetic Diagnosis?” Stanford Law School, February 27, 2004.

“Evaluating the Safety of Medical Products: Failures and Successes in Law and Regulation,” Research and the Law: A Working Conversation on Scientific Research in the Courtroom, National Judicial Institute, Toronto, February 23, 2004.

Presenter and Moderator, “Germ-Line Modifications and Human Subjects Research: An Ethical and Policy Examination,” Joint Meeting, American Society for Bioethics and Humanities and Canadian Bioethics Society, Montreal, October 25, 2003.

“Public Bioethics: A View from the President’s Council,” Hastings Center Fellows Meeting, Montreal, October 22, 2003.

Participant, Panel on Human Cloning, Joint Meeting of New York Society of Reproductive Medicine and New York Metropolitan Embryology Society, New York City, September 10, 2003.

“Biomedical Research Cloning: Should We or Shouldn’t We?” Carleton College Convocation, Northfield, Minnesota, May 23, 2003.

“Special Respect and Public Deliberation: Two Neglected Elements of the Stem Cell Debate,” Bioethics Seminar Series, Wake Forest University School of Medicine, May 8, 2003.

Discussant, Surrogates Decision-Making, Ethics Grand Rounds, National Institutes of Health, Bethesda, Maryland, May 7, 2003.

Panelist, “Who Decides? Reproductive Technologies, Ethics, and the Law,” Mount Holyoke College, South Hadley, Massachusetts, March 27, 2003.

“Stem Cell Research: What It Is ... and What It Isn’t,” Women’s Health Coalition Annual Conference, Santa Barbara, California, February 22, 2003.

“The American Experience: Strangers at the Bedside,” Biolaw and Bioethics: A Mandatory Cooperation, Institute of Bioethics - Foundation for Health Sciences, Madrid, Spain, February 5, 2003.

Panelist, “Beyond Dolly: Human Cloning and Human Dignity,” University of Maryland School of Law and Johns Hopkins University Bioethics Institute, Baltimore, Nov. 21, 2002.

“Precommitment: A Misguided Strategy for Securing Death With Dignity,” Faculty Workshop, School of Law, University of North Carolina at Chapel Hill, November 15, 2002.

“Human Embryonic Stem Cell Research: Arguments and Advocacy,” Merrimon Lecture, School of Medicine, University of North Carolina at Chapel Hill, November 14, 2002.

“Protection or Disrespect: Courts and the Conscious Incompetent Patient,” Plenary Session, 5<sup>th</sup> Annual Meeting, American Society for Bioethics and Humanities, Baltimore, October 25, 2002.

“Stem Cell Research: Ethics and Advocacy,” Harvard University Center for Ethics and the Professions Lecture Series, Cambridge, October 3, 2002.

“Ethical and Policy Issues for the Aging Population.” Joint Meeting of the American Psychiatric Association Council on Psychiatry and Law and Committee on Judicial Action, Washington, DC, September 13, 2002.

“Patient Advocacy and Research Ethics,” “The News Media and Research Ethics,” and “Patient Advocates as Public Members of IRBs,” University of Texas Medical Branch at Galveston, March 7-8, 2002.

“When Science Offers Salvation: Patient Advocacy and Research Ethics,” Association of American Medical Colleges Annual Meeting, Washington, DC, November 5, 2001.

Panel, “Bioethics and Activism,” American Society for Bioethics and Humanities Annual Meeting, Nashville, Tennessee, October 27, 2001.

“Surrogate Issues for Incapacity,” Royal Society of Medicine, London, October 15, 2001.

“Stem Cell Research: Science, Ethics, and Policy,” Shell Science Symposium, National Science Teachers Association National Convention, St. Louis, March 24, 2001.

“The Ethics of Research Advocacy,” 21<sup>st</sup> Annual Bioethics Winter Lecture Series, University of Minnesota, March 15, 2001.

“Patient Advocates and NIH Funding,” Office of Science Policy, National Institutes of Health, Bethesda, January 26, 2001.

“Priority Setting in Research Funding,” Hastings Center Annual Fellows Meeting, Garrison, New York, October 14, 2000.

“Genes for Criminality: Should We Allow Research and Testing?” DeCamp Bioethics Center and Institute for Genomic Analysis Colloquium, Princeton University, October 4, 2000.

“Storage and Use of Gametes and Embryos: Arguments For and Against Regulation,” Legal Challenges in Genetics and Reproductive Medicine, American Society of Law, Medicine & Ethics, Boston, September 15, 2000.

Keynote Address, “Bioethics: The Next Twenty-Five Years,” Center for Applied and Professional Ethics, University of Tennessee, Knoxville, April 7, 2000.

Annual Lectureship in Toxicology, “The Rule of Double Effect,” American Academy of Forensic Sciences Annual Meeting, Reno, Nevada, February 25, 2000.

“Human Studies and Species Boundaries Issues,” Conference on Genes and the Just Society, University of San Diego Law School, January 29, 2000.

Panelist, “Issues in Ethics: Psychiatric Research,” Annual Meeting, American College of Neuropsychopharmacology, Acapulco, Mexico, December 12, 1999.

“Advance Research Directives: Information Disclosure and Participant Protection,” Annual Meeting, American Society for Bioethics and Humanities, Philadelphia, October 31, 1999.

“Government Priorities for Biomedical Research: What Does Justice Require?” Third Annual Colloquium, Faculty of Laws, University College, London, July 5, 1999.

“Controversies in Biomedical Research Policy,” Plenary Session, 20<sup>th</sup> Annual Health Law Teachers Conference, St. Louis, June 4, 1999.

“When Does No Mean No? Dissent and Assent by Research Participants Unable to Give Informed Consent,” John F. Kennedy Center for Research on Human Development, Vanderbilt University, April 27, 1999.

“Disease Advocacy and Allocation of Federal Funds for Biomedical Research,” Annual Meeting, Association for Practical and Professional Ethics, Washington, February 27, 1999.

Commentator, “Institute of Medicine Report on Priority Setting at the National Institutes of Health,” Biomedical Research: Problems, Possibilities, Puzzles, and Priorities, National Press Club, Washington, February 1, 1999.

“The National Bioethics Advisory Commission’s Report and Its Potential Impact on Psychiatric Research,” Eleventh Annual New York State Office of Mental Health Research Conference, Albany, New York, December 2, 1998.

“Consent Planning: Ethical and Practical Considerations,” Research Involving Persons with Mental Disorders That May Affect Decision-Making Capacity, Second National Ethics Conference, Baltimore, November 14, 1998.

Panelist, “How Should Public Policy Be Made? Public Participation and Consensus,” Ethical and Policy Issues in Xenotransplantation, Hastings Center Fellows Meeting, October 17, 1998.

“Parenthood in Assisted Reproduction: Legal Principles and Uncertainties,” Medicine in a Moral Fog—Are We Going Too Far? Colorado Springs, October 15, 1998.

Plenary Session, “NBAC Report on Research Involving Persons with Mental Disorders Affecting Decision-Making Capacity,” Tenth Annual Bioethics Summer Retreat, Cape Cod, June 18, 1998.

“Genetic Testing and Insurance: Ethical and Policy Issues,” Collaborative Group of the Americas on Inherited Colorectal Cancer, St. Louis, June 13, 1998.

Panelist, “Science in Litigation,” American Society of Law, Medicine & Ethics Health Law Teachers Conference, Houston, June 5, 1998.

“The Supreme Court and End-of-Life Care: Principled Distinctions or Slippery Slope?” University of Michigan Law School, November 15, 1997.

“Research from the Consumer’s Perspective,” Genetics and Brain Disorders: Fact, Fiction and Ethics, Family Caregiver Alliance 20th Anniversary Conference, San Francisco, October 20, 1997.

“Research Ethics and Persons with Mental Disabilities: The More Things Change...,” Mental Health and the Law: A 25-Year Retrospective, University of Virginia Institute of Law, Psychiatry & Public Policy Twentieth Anniversary Conference, Charlottesville, October 30, 1997.

Discussion of Contract Paper on Research Involving Persons With Mental Disabilities, National Bioethics Advisory Commission, Bethesda, Maryland, July 15, 1997.

“Advance Directives: A Reconsideration,” Keynote Address, Health Care, Law and the Life Cycle Colloquium Series, University of Colorado Health Sciences Center, May 20, 1997.

Guest Presenter, Research Involving Cognitively Impaired Persons, National Bioethics Advisory Commission, Washington, January 10, 1997.

Faculty, Institutional Animal Care Committees: Current Issues and Future Growth, Scientists Center for Animal Welfare, San Antonio, December 5-6, 1996.

"Advance Directives in Research on Mental Disorders: A Critique," III World Congress of Bioethics, San Francisco, November 24, 1996.

"Ethical and Regulatory Aspects of Prospective Use of Radioprotectors," U.S. Department of Energy Consensus Conference on Use of Radioprotector Ethylol for Planned Radiation Exposures During Emergencies, Bethesda, Maryland, August 15-16, 1996.

"Criminal Responsibility and the 'Genetics Defense,'" University of Utah Workshop on Genetic Testing and Screening for Mental Health Disorders, Snowbird, Utah, June 5-9, 1996.

"Prior Preferences and Present Interests: Which Matters Most?" Keynote Address, Annual Meeting, Michigan Ethics Review Network, Ann Arbor, May 18, 1996.

"Urban Women as Biomedical Research Subjects: Current Ethical and Policy Challenges," Fifth Annual Feminist Symposium, Northwestern University School of Law, April 1, 1996.

"Critique of the HHS Commission on Research Integrity," Meeting of Committee on Research Integrity, Association of American Medical Colleges, Washington, February 16, 1996.

"Preserving Dignity and Maximizing Quality of End of Life," Communication & Ethics: Working with Individuals and Families Facing Dementia, Cleveland, November 9, 1995.

"Should We Individualize, Expand, or Abandon the Law on Determination of Death?" Defining Death in a Technological Age, Cleveland, November 4, 1995.

Panelist, "How I See This Case," Ninth Annual Meeting, Society for Bioethics Consultation, Cleveland, September 15, 1995.

"Institutional Animal Care and Use Committees: Virtues, Drawbacks, and Future," Ethical Issues of Animal Use, Kennedy Institute of Ethics, Georgetown University, June 28, 1995.

"Standards for Responsible Surrogacy," Seventh Annual Bioethics Summer Retreat, Winthrop, Washington, June 17, 1995.

"Ethics and Law of End-of-Life Decision Making," Assisted Suicide: Medical, Ethical & Legal Issues, Toledo Hospital, May 9, 1995.

"Who Is a 'Normal' Research Subject?" 56th Annual Biology Colloquium, Oregon State University, April 20, 1995.

"Decisions on Life-Sustaining Treatment for Patients with Dementia," Bioethics Grand Rounds, Cleveland Clinic Foundation, February 10, 1995.

"Professional Conscience and the Doctor-Patient Relationship," Hastings Center Conference on Truth in Health Care, Detroit, November 12, 1994.

Visiting Professor in Medicine and Medical Ethics, University of Pittsburgh, October 13-14, 1994.



Invited Panelist, Symposium on Ronald Dworkin's *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*, Bioethics Concurrent Meeting, Pittsburgh, October 8, 1994.

Faculty, Ethical Issues on Animal Use in Research and Education, Kennedy Institute, Georgetown University, July 13-14, 1994.

Panelist, "The Public and the Private--Redrawing Boundaries," Hastings Center 25th Anniversary Conference, New York, June 4, 1994.

"Legal Issues in Futility Cases," Medical Futility: Ethical, Medical, Legal, and Economic Implications, Cleveland, April 23, 1994.

Nancy Rhoden Memorial Lecture, Oberlin College Department of Philosophy, February 28, 1994.

"Professional Conscience and Access to Abortion," Annual Meeting, Association of Practical and Professional Ethics, Cleveland, February 25, 1994.

"The Artificial Heart in the Clinical Setting: Promoting Information, Minimizing Harm, and Allocating Losses," National Heart, Lung, and Blood Institute Workshop on the Artificial Heart: Planning for Evolving Technologies, Bethesda, Maryland, January 25, 1994.

"Decisions on Life-Sustaining Treatment: Incorporating the Dementia Patient's Perspective," Ohio Legal Theory Workshop, Ohio State University College of Law, September 17, 1993.

"Feminist Bioethics," Health Law Teachers Conference, Baltimore, June, 1993 (with Susan Wolf).

"Life-Sustaining Treatment and Dementia Patients," Division of Medical Ethics, Harvard Medical School, May, 1993.

"Refining the Best Interests Standard," Conversations on Ethics, Children's Hospital, Boston, April, 1993.

Panelist, "Values and Ethics," Animal Research Committees: Ethics, Education, and Economics, Public Responsibility in Medicine and Research, Boston, March, 1993.

"Justice and Gender in Biomedical Research Policy," Harvard School of Public Health, March, 1993.

Panelist, "Special Issues Involving Women's Health Research," IRB Review: The Changes and the Challenges, Public Responsibility in Medicine and Research, Boston, December, 1992.

"Treatment Standards for Incompetent Patients," School of Law, Washington University, St. Louis, November, 1992.

"Reproductive Technology and Multiple Birth: Legal and Ethical Issues," Seventh International Congress on Twin Studies, Tokyo, June, 1992.

"Ethics of Animal Patenting," Hastings Center Project on Animal Biotechnology, Briarcliff Manor, N.Y., April, 1992.

"Animal Care Committees: Between the Scientific Community and the Government," International Conference on Science and the Human-Animal Relationship, Amsterdam, March, 1992.

"Ethical Perspectives on Transgenic Animals," Dilemmas in Rodent Research: Scientific, Regulatory, Ethical Perspectives, National Institutes of Health, Office of Protection from Research Risks and University of Texas Health

Science Center, Houston, Texas, December, 1991.

"Understanding Ethical Issues Posed By the Patient Self-Determination Act," Hastings Center Workshop on Implementing the Patient Self-Determination Act, New York Academy of Medicine, November, 1991.

"Standards for Animal Research: Justification and Assessment for Alternatives," Special Symposium on Animal Welfare and Alternatives to Animals, Annual Meeting, American Veterinary Medical Association, Seattle, July, 1991.

Case Analysis, Invitational Working Conference on Ethics in Case Management, University of Minnesota Long-Term Care Decisions Resource Center, July, 1991.

Panelist, "Futility: Termination of Life Support against Family Wishes," Third Annual Bioethics Retreat, Nantucket, June, 1991.

Panelist, "Selected Issues on the Well-Being of Animals Used in Research, Testing and Education," Scientists Center for Animal Welfare, Philadelphia, Pennsylvania, June, 1991.

Faculty, "Ethical Issues in Animal Experimentation," Kennedy Institute of Ethics, Georgetown University, March, 1991.

"Biomedical Technology and the Right to Privacy," Federal Judicial Center Conference, Case Western Reserve University Law School, March, 1991 and October, 1989.

"The Multiple Self and Individual Responsibility," Difficult Rights, University of Milan, Italy, May, 1990.

"Must We Do All That We Can Do? Autonomy, Advance Directives, and the Refusal of Life-Sustaining Treatment," Dementia: Moral Values and Policy Choices in an Aging Society, Alzheimer Center, University Hospitals of Cleveland and Center for Biomedical Ethics, Case Western Reserve University, April, 1990.

"Autonomy and Quality of Life in Medical Decision Making: Nancy Rhoden's Contribution," Fourth Annual Hunter Lectureship in Child Health, Law and Ethics, Albert Einstein College of Medicine and Montefiore Medical Center, New York, April, 1990.

"Philosophical Problems in Decision-Making for Incompetent Patients," Bioethics Retreat, Lutsen, Minnesota, July, 1989.

Panelist, "Facing Life and Death Issues With Hope," Myers Park Baptist Church, Charlotte, North Carolina, May, 1989.

Panelist, "The Administration and Function of Effective Animal Care Committees," Public Responsibility in Medicine and Research and Tufts University School of Veterinary Medicine, Boston, March, 1989.

"Ethical and Legal Perspectives on Animal Research," Cleveland Clinic, October, 1988.

"Legal Issues in Terminating Life-Sustaining Treatment," Iowa State Judges Conference, Des Moines, June, 1988.

"Legal and Ethical Issues in Patenting New Animal Life," Arizona State University College of Law, March, 1988.

"Human-Animal Organ Transplants," People as Products, Public Responsibility in Medicine and Research, Houston, February, 1988.

"Limiting Living Wills," University of New Mexico School of Law, January, 1988.

"Electric Shock as an Aversive Stimulus in Animal Research: Ethical and Regulatory Issues," National Institute of Mental Health/National Institute of Drug Abuse Workshop on Neuroscience Methods, Bethesda, Maryland, December, 1987.

"Nontreatment Standards for Incompetent Patients," University of Arizona College of Law, November, 1987.

"Passive Euthanasia," Technocracy Ethics: Live or Let Die? St. David's Community Hospital, Austin, Texas, September, 1987.

"Handicapped Infants," Bioethics: Reality and Clinical Practice Today, University of Florida College of Medicine, Gainesville, May, 1987.

"Laws and Governmental Intervention," Medical Problems Before and After Birth: Clinical Information and Pastoral Concerns, Institute of Religion and March of Dimes Birth Defects Foundation, Houston, Texas, April, 1987.

"The New Reproductive Technologies: Who Shall Benefit?" Dimensions in Women's Health Care: Education, Services, Research, University of Texas-Houston School of Nursing, April, 1987.

Panelist, "Making Your Animal Care Committee Work: Current Issues and Practical Problems," Public Responsibility in Medicine and Research and Tufts University School of Veterinary Medicine, Boston, March, 1987.

"The Dietician and the Law," Baton Rouge Dietetic Association, March, 1987.

"Patients' Rights and Providers' Responsibilities Under the Texas Natural Death Act" and "Nontreatment Decisions: Legal and Ethical Issues," Ethics at the End of Life, Educational Institute on Aging, Austin, Texas, January, 1987.

"Ethical Perspectives on Animal and Human Euthanasia," Annual Meeting, American Association for Laboratory Animal Science, Chicago, October, 1986.

"Contemporary Ethical Perspectives on Animal Research: From Humane Treatment to Animal Rights," Annual Meeting, American Association for Laboratory Animal Science, Texas Branch, College Station, May, 1986.

Panelist, "Animals and Research: A Film Forum," Department of Humanities and Communications, Drexel University, Philadelphia, April, 1986.

"Legal Issues in Decision-Making for Incompetent Patients: Refining the Best Interests Standard," Ethical Issues in Health Care for the Elderly, University of Tennessee Center for the Health Sciences, Memphis, April, 1986.

"Ensuring Equitable Access to the New Reproductive Techniques," High Tech Baby-Making: Its Technology and Social, Ethical and Legal Implications, Women's Research Institute, Hartford, Connecticut, March, 1986.

"Death with Dignity: Patients' Rights and the Texas Hospice Movement," Angelo State University, San Angelo, Texas, February, 1986.

"Baby Doe: The Federal Legislation and the Ethical Controversy," Bioethics Lecture Series, University of Texas at San Antonio Health Science Center, February, 1986.

Symposium Participant, "Ethical and Legal Issues in Initiating and Withdrawing Nutritional Support," Tenth Clinical Congress, American Society for Parenteral and Enteral Nutrition, Dallas, Texas, February, 1986.

Round Table Participant, "Infant Care Review Committees," American Academy of Pediatrics Annual Meeting, San Antonio, October, 1985.

"Research Ethics," Plenary Session, Academy of Surgical Research, San Antonio, October, 1985.

"The Limits of Advance Directives," Spring National Meeting, Society for Health and Human Values, Little Rock, Arkansas, May, 1985.

"Discontinuing Nutritional Support: The Court Decisions," Ethical and Legal Issues in Withdrawing Treatment from Critically or Terminally Ill Patients, School of Nursing, University of Texas at Austin, March, 1985.

"Withholding Nutritional Support: Review of the Case Law," Annual Meeting, American Dietetic Association, Washington, October, 1984.

"The Role of Advance Treatment Directives in Health Care Policy," Third International Conference on System Science in Health Care, Munich, July, 1984.

"Social Justice in New Reproductive Techniques," Genetics and the Law: Third National Symposium, Boston, April, 1984.

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