

Curriculum Vitae
Benjamin Simon Wilfond
e-mail:wilfond@nih.gov

CURRENT POSITION

Head, Section on Ethics and Genetics
Department of Clinical Bioethics
Warren G. Magnuson Clinical Center
National Institutes of Health, Bethesda, MD

Head, Bioethics Research Section
Medical Genetics Branch
National Human Genome Research Institute
National Institutes of Health, Bethesda, MD

CURRENT MEDICAL STAFF APPOINTMENTS

Warren G Magnuson Clinical Center
Bethesda, MD

Johns Hopkins Hospital
Baltimore, MD

Mount Washington Medical Center
Baltimore, MD

EDUCATION

1981-1985 **M.D.**
University of Medicine and Dentistry of New Jersey-
New Jersey Medical School
Newark, NJ

1977-1981 **B.S.**
Muhlenberg College
Allentown, PA

POSTDOCTORAL TRAINING

1988-1991 **Fellowship**
Division of Pulmonology and Cystic Fibrosis
Department of Pediatrics
Program in Medical Ethics
Department of History of Medicine
University of Wisconsin, Madison, WI

1985-1988 **Residency**

Department of Pediatrics
University of Wisconsin Hospital and Clinics
Madison, WI

OTHER AND PREVIOUS ACADEMIC POSITIONS

- 1998 – present **Visiting Associate Professor**
Department of Pediatrics
Johns Hopkins University
Baltimore, MD
- 1998 **Associate Professor** (with tenure)
Department of Pediatrics
University of Arizona
Tucson, AZ
- 1992-1998 **Assistant Professor**
Department of Pediatrics
University of Arizona
Tucson, AZ
- 1991-1992 **Instructor**
Department of Pediatrics
University of Wisconsin
Madison, WI

EDITORIAL POSITIONS

- 2002-present **Editorial Board**
American Journal of Bioethics
- 1995-1999 **Editorial Board**
American Journal of Medical Genetics

CURRENT BOARDS AND OTHER POSITIONS

- 2002 **Member**
Project on Ethical Decision-Making for Newborn Screening
Hastings Center
- 2001-present **Member**
Executive Committee
National Center for Genome Research / Johns Hopkins
University Genetics Counseling Training Program

2001-present	Member Childhood Asthma Research and Education Network Data and Safety Monitoring Board National Heart Lung and Blood Institute
2001-present	Co chair Ethics Working Group National Children's Study National Institute of Child Health and Development
2000-present	Member Ethics Committee Warren G. Magnuson Clinical Center
2000-present	Member NIH Committee on Scientific Conduct and Ethics Division on Intramural Research
2000-present	Member Data Safety and Monitoring Committee Cystic Fibrosis Foundation
1999-present	Attending Bioethics Consultation Service Department of Clinical Bioethics Warren Grant Magnuson Clinical Center
1999-present	Member Pediatric Ethics Working Group Food and Drug Administration
1998-present	Associate Chair Institutional Review Board National Human Genome Research Institute

*PAST BOARD AND COMMITTEE POSITIONS
HOSPITALS AND UNIVERSITIES*

1998	Chair Ethics Committee University Medical Center Tucson AZ
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1997-1998 **Member**
Ethics Committee
Tucson Medical Center
Tucson AZ

1997-1998 **Member**
Ethics Committee
Pima County Medical Society
Tucson AZ

1996-1998 **Member**
Genetic Counseling Training Program Admissions Committee
University of Arizona

1996-1998 **Member**
Department of Pediatrics
Human Subjects Committee
University of Arizona

1996-1998 **Member**
Cancer Genetics Steering Committee
Arizona Cancer Center

1995-1998 **Member**
Asthma Task Force
University Medical Center

1993-1998 **Member**
Human Subjects Committee
University of Arizona

1992-1998 **Member**
Ethics Committee
University Medical Center

1987-1992 **Member**
Hospital Ethics Committee
University of Wisconsin Hospital and Clinics

1988-1992 **Member**
Human Subjects Committee
University of Wisconsin Hospital and Clinics

1988-1992 **Member**
Ethics Committee

Meriter Hospital
Madison, WI

OTHER PAST BOARD AND COMMITTEE POSITIONS

2001-2002	Co-chair Informed Consent/IRB Working group Secretary's Advisory Committee on Genetic Testing Department of Health and Human Services
2001	Study Section Member Newborn Screening Grant Review Committee Health Services Resource Administration
2000-2002	Member Institutional Review Board National Institute of Child Health and Development
1999- 2000	Member Institutional Review Board National Heart Lung and Blood Institute
2000	Member Annual Meeting Program Committee American Society of Bioethics and Humanities
1999-2001	Member Clinical Trial of Oral Pirfenidone for the Pulmonary Fibrosis of Hermansky Pudlak Syndrome Data Safety and Monitoring Committee National Institute of Child Health and Development
1999-2000	Member Newborn Screening Taskforce (working group member) American Academy of Pediatrics/Health Services Resource Administration
1999-2000	Member Screening and Detection Working Group Alpha One Foundation
1999	Member Working Group on Communicating Informed Consent to Individuals Who Are Deaf or Hard of Hearing

- National Institute for Deafness and Communication Disorders
- 1998 **Member**
Working Group on Considerations for Developing and Implementing Genetic Diagnostic Tests for Hereditary Hearing Impairment and Other Communication Disorders.
National Institute for Deafness and Communication Disorders
- 1998-1999 **Member**
Working Group on Cystic Fibrosis Educational Materials
National Human Genome Research Institute
- 1997-1999 **Member**
Working Group on Umbilical Cord Blood Banking
American Academy of Pediatrics
- 1997 **Participant**
Workshop on Newborn Screening for Cystic Fibrosis: A paradigm for public health genetics policy development
Center for Disease Control and Prevention
- 1997 **Participant**
Workshop on Iron Overload, Public Health, and Genetics
Center for Disease Control and Prevention
- 1997 **Participant**
Workshop on Ethical Issues in Umbilical Cord Blood Banking
National Heart Lung and Blood Institute
- 1996-2002 **Member**
Committee on Bioethics
American Academy of Pediatrics
- 1996 **Planning Committee Member**
Consensus Development Conference for Genetic Testing for Cystic Fibrosis
Office of Medical Applications of Research, NIH
- 1996-1998 **Core Member**
Project on Prenatal Diagnosis and Disability
Hastings Center
- 1996-1998 **Participant**

Workshop on Early Interventions to Prevent Asthma Project
on Prenatal Diagnosis and Disability
National Heart Lung and Blood Institute

1995-1998 **Consultant**
Cancer Genetic Studies Consortium
National Human Genome Research Institute

1994 **Study Section Member**
ELSI Proposals
Department of Energy

1994 **Study Section Member**
Studies of Genetic Testing and Counseling for Heritable Cancer
Risks
National Human Genome Research Institute

1993-1997 **Member**
Bioethics Task Force
American Thoracic Society

1992-1995 **Member**
Social Issues Committee
American Society of Human Genetics

1992-1995 **Chairman**
Subcommittee on genetic testing of children
Social Issues Committee
American Society of Human Genetics

1992-1994, 1998 **Reviewer**
Genetics Abstracts
North American Cystic Fibrosis Conference
Moderator for workshops on genetic counseling,
carrier testing, and newborn screening
Cystic Fibrosis Foundation

1991-1993 **Participant**
Project on Clinical Priorities in the Application of Human
Genetic Research
Hastings Center

1991-1994 **Consultant**
Cystic Fibrosis Studies Consortium
National Center for Genome Research

- 1990 **Participant**
Workshop on the Introduction on New Genetic Tests
NIH-DOE Working Group on Ethical, Legal and Social
Implications (ELSI) of Human Genome Research
- 1989-1999 **Member**
Program Committee
Student Interest Group
Society for Health and Human Values
- 1984-1985 **Founder and National Coordinator**
Standing Committee on Bioethics
American Medical Student Association
- 1983-1984 **Member**
Board of Trustees
American Medical Student Association
- 1983 **Coordinator**
AMSA Region II Conference
American Medical Student Association
- 1982-1983 **Co-President**
AMSA Chapter
New Jersey Medical School
American Medical Student Association

PAST POSITIONS

- 1997-1998 **Co-Director**
Cystic Fibrosis Center
Pediatric Pulmonary Section
University of Arizona
- 1995-1997 **Associate Director**
Cystic Fibrosis Center
Pediatric Pulmonary Section
University of Arizona
- 1993-1998 **Director**
Pediatric Pulmonary Section
Infant Apnea/Bronchopulmonary Dysplasia Program
University of Arizona

MEDICAL CERTIFICATION

CERTIFICATION

1986 National Board of Medical Examiners #308516
1989 American Board of Pediatrics #41759
1992 Sub-Board of Pediatric Pulmonology #371

LICENSURE

1986 State of Wisconsin #27881 (inactive)
1992 State of Arizona #20606
1998 State of Maryland # D54108

AWARDS AND HONORS

1989-1990 **Clinical Fellowship**
Cystic Fibrosis Foundation

1994-1999 **FIRST Award**
Agency for Health Care Policy and Research

1996-1997 **Fellowship**
Udall Center for Studies in Public Policy
University of Arizona

PUBLICATIONS

BOOK CHAPTERS

Gollust S and Wilfond B. *Population carrier screening: psychological impact of* Encyclopedia of the Human Genome. New York::Nature Publishing Group 2003 (in press)

Wilfond BS. *Genetic Testing* in Sugarman J, ed. Ethics in Primary Care. McGraw-Hill, New York, NY 2000:67-77

Wilfond BS and Thomson E. *Models of public health genetic policy development in* Khoury MJ, Burke W, and Thomson E, eds Genetics and Public Health in the 21st Century: Using genetic information to improve health and prevent disease. Oxford University Press, New York, NY. 2000:61-81

Wilfond B and Taussig LM. *Cystic Fibrosis: Clinical Overview* in Taussig LM and Landau LI, eds. Textbook of Pediatric Pulmonary Medicine Mosby-YearBook, St Louis, MO. 1999:982-990

Wilfond B. *A Questionable Parental Request* in Iserson KV, Sanders AB, and Mathieu M. eds Ethics in Emergency Medicine. 2nd Ed. Galen Press, Tucson, AZ. 1995:223-229

JOURNAL ARTICLES

Koogler T, Wilfond B and Ross LF. Lethal Language, Lethal Decisions. *Hastings Center Report* 2002 (in press)

Hornig S, Emanuel EJ, Wilfond B, Rackoff J, Martz K, Grady G. Do Consent Forms for Phase I Oncology Trials Over Promise Benefits and Downplay Risks? *N Engl J Med* 2002 (In press)

Miler F, Wendler D, and Wilfond B. When do the federal regulations allow placebo controlled trials. *J Peds* 2002 (in press)

Davis AM, Hull SC, Grady G, Wilfond BS and Henderson GE. The Invisible Hand in Clinical Research: The Study Coordinator's Critical Role in Human Subjects Protection. *Journal of Law Medicine and Ethics* 2002 (in press)

Gollust SE, Hull SC, Wilfond BS. Limitations of Direct-to-Consumer Advertising for Clinical Genetic Testing. *JAMA*. 2002 288:1762-7

Wilfond B and Rothenberg LS Ethical issues in cystic fibrosis newborn screening: from data to public policy *Curr Op Pulm Med* 2002 8:529-534

Fruend C and Wilfond BS. Emerging ethical issues in pharmacogenomics. *American Journal of Pharmacogenomics* 2002; 2:273-281

Wendler D, Prasad K and Wilfond B. Does the current consent process minimize the risks of genetics research? *American Journal of Medical Genetics* 2002; 113:258-262

Gooding H, Wilfond B, Boehm K, and Biesecker BB. Unintended Messages: The ethics of teaching genetics dilemmas. *Hastings Center Report* 2002 32:37-9.

Hedenfalk I, Duggan D, Chen Y, Radmacher M, Bittner M, Simon R, Meltzer P, Gusterson B, Esteller M, Kallioniemi O, Wilfond B, Borg A, and Trent J. Gene expression profiles distinguish hereditary breast cancers. *N Engl J Med* 2001 344: 539-548.

Burger I, Wilfond BS. Limitations of Informed Consent for In Utero Gene Transfer Research: Implications for Investigators and Institutional Review Boards. *Human Gene Therapy* 2000; 11:1053-1067

Wilfond BS. Genetic testing of umbilical cord blood samples: The role of parental permission and nondisclosure of genetic information. *Cancer Research Therapy and Control* 1999; 8:347-349

Smith FO, Kurtzberg J, Karson EM, Wilfond B, Broxmeyer H, Mastroianni AC, Gross S, Sugarman J. Umbilical Cord Blood Collection, Storage and Transplantation: Issues and recommendations for expectant parents and patients. *Cancer Research Therapy and Control* 1999; 10:217-226

Mischler E, Wilfond BS, Fost N, Laxova A, Reiser C, Sauer CM, Makhholm LM, Shen G, Feenan L, McCarthy C, Farrell PM. Cystic fibrosis newborn Screening: Impact on reproductive behavior and implications for genetic counseling. *Pediatrics* 1998; 102:44-52

Burke W, Thomson E, Khoury M, Mc Donnell S, Press M, Adams P, Barton JC, Beutler E, Buchanan A, Clayton EW, Cogswell ME, Meslin E, Motulsky A, Powell LW, Sigal E, Wilfond BS, Collins FS. Hemochromatosis: Gene discovery and its implications for population-based screening. *JAMA* 1998; 280:172-178

Ozdemer A, Costentino C, Siwik SA, Wilfond BS. Orange Seed Aspiration. *Arch Pediatr Adolesc Med* 1998; 152:921-922

Loeben G, Marteau MM, Wilfond BS. Mixed Messages: Presentation of information in cystic fibrosis screening pamphlets. *Am J Hum Genet.* 1998; 63:1182-1190

Loeben G, Wilfond BS. What we should learn about communication from the placebo effect. *Ethics and Behavior* 1998; 8:89-98

Lerman C, Gold K, Audrain J, Lin TS, Boyd N, Orleans CT, Wilfond B, Loeben G, Caporaso N. Incorporating Biomarkers of Exposure and Genetic Susceptibility into smoking cessation treatment: Effects on smoking-related cognitions, emotions, and behavior change. *Health Psychology* 1997; 16:87-99

Geller G, Botkin B, Green M, Press P, Biesecker B, Wilfond B, Grana G, Daly M, Schneider K, and Kahn MJ. Informed consent for genetic testing for cancer predisposition: Report of the task force on informed consent of the NIH Cancer Genetic Studies Consortium. *JAMA* 1997; 277:1467-1474

Sugarman J, Kaalund V, Kodish E, Marshall MF, Reisener EG, Wilfond BS, Wolpe PR and the Working Group on Ethical Issues in Umbilical Cord Blood Banking. Ethical issues in umbilical cord blood banking. *JAMA* 1997; 278:938-943

Wilfond BS, Rothenberg K, Thomson E, Lerman C, on behalf of the Cancer Genetic Studies Consortium, National Institutes of Health. Cancer Genetic Susceptibility Testing: Ethical and Health Implications for Future Research and Clinical Practice. *Journal of Law Medicine and Ethics* 1997; 25:243-251

Wilfond BS. Screening policy for cystic fibrosis: The role of evidence. *Hastings Center Report* 1995; 25:S21-S23

Wilfond BS, Baker, D. Meaning what I say is not saying what I mean: Genetic counseling, non-directiveness and patient values. *J Clin Ethics* 1995; 5:181-182.

Wilfond BS, Farrell PM, Laxova A, Mischler EH. Severe hemolytic anemia associated with vitamin E deficiency in infants with CF: Implications for neonatal screening. *Clin Ped* 1994; 33:2-7

Wilfond BS, Nolan K. National policy development for the clinical application of genetic diagnostic technologies: lessons for cystic fibrosis. *JAMA* 1993; 270:2948-2954

Gregg RG, Wilfond BS, Farrell P, Laxova A, Hassemer D, Mischler E. Application of DNA analysis in a population screening program for neonatal diagnosis of cystic fibrosis; Comparison of Screening Protocols, *Am J Hum Gen* 1993; 52:616-626

Lippman A, Wilfond BS, "Twice-told tales: stories about genetic disorders. *Am J Hum Gen* 1992; 51:36-37

Wilfond BS and Fost N. Cystic fibrosis carrier screening; The introduction of cystic fibrosis carrier screening into clinical practice: policy considerations. *Milbank Quarterly* 1992; 70:629-65

Farrell PM, Mischler EH, Fost NC, Wilfond BS, Tluczek A, Gregg RG, Bruns W, Hassemer DJ, and Laessig RH. Current issues in neonatal screening for cystic fibrosis and implications of the CF gene discovery. *Peds Pulm Suppl* 1991; 7:11-18

Wilfond BS and Fost N. The CF gene: Medical and social implications of heterozygote detection. *JAMA* 1990; 263:2777-2783

PROFESSIONAL ORGANIZATION POLICY PAPERS

American Academy of Pediatrics, Committee on Bioethics. Institutional Ethics Committees *Pediatrics* 2001. 107:205-209

Nelson RM, Botkin JR, Kodish ED, Levetown M, Truman JT, Wilfond BS, Harrison CE, Kazura A, Krug E 3rd, Schwartz PA, Donovan GK, Fallat M, Porter IH, Steinberg D. Ethical issues with genetic testing in pediatrics. *Pediatrics*. 2001; 107:1451-5

American Academy of Pediatrics, Committee on School Health and Committee on Bioethics. Do Not Resuscitate Orders in Schools. *Pediatrics* 2000. 105: 878-879

American Academy of Pediatrics, Committee on Bioethics. Palliative Care for Children. *Pediatrics* 2000; 106:351-357

American Academy of Pediatrics, Newborn Screening Taskforce. Newborn Screening: A Blueprint for the Future. *Pediatrics* 2000; 106:389-427

American Academy of Pediatrics, Committee on Child Abuse and Neglect and Committee on Bioethics. Forgoing Life-Sustaining Medical Treatment in Abused Children. *Pediatrics* 2000; 106: 1151-1153

American Academy of Pediatrics, Working Group on Cord Blood Banking. Cord Blood Banking for Potential Future Transplantation: Subject Review. *Pediatrics* 1999; 104:116-118

American Academy of Pediatrics, Committee on Bioethics Appropriate Boundaries in the Pediatrician-Family-Patient Relationship. *Pediatrics* 1999; 104:334-336

American Academy of Pediatrics, Committee on Bioethics. Sterilization of Minors with Developmental Disabilities. *Pediatrics* 1999; 104: 337-340

American Academy of Pediatrics, Committee on Bioethics. Female Genital Mutilation. *Pediatrics* 1998; 102:153-156

American Thoracic Society Board of Directors. Fair Allocation of Intensive Care Unit Resources. *Am J Respir Crit Care Med* 1997; 156:1282-1301

American Society of Human Genetics and Medical College of Medical Genetics Board of Directors. Points to consider: Ethical, legal and social implications of genetic testing with children. (Corresponding author) *Am J Hum Gen* 1995; 57:1233-1241

LETTERS AND COMMENTARIES

Botkin JR, Clayton E, Nelson R, Wilfond B, Munger MA. Salmeterol and inhaled corticosteroids in patients with persistent asthma. *JAMA*. 2001 286:3075; 3077-8.

Wilfond BS. Genetic testing, not cloning, is worrisome. (Guest commentary) *Arizona Daily Star*. March 1997

Wilfond BS. Genetic testing should be deferred until adulthood. (commentary) *AAP News*. November 1996

Wilfond BS, Genetic Testing in Children.(commentary) *Perspectives in Genetic Counseling* 1995 17:9

Biesecker L, Wilfond B. Generic Consent for Genetic Screening. (letter) *NEJM* 1994 331:1024

Biesecker L, Bowles-Biesecker B, Collins F, Kaback M, Wilfond B. General population screening for cystic fibrosis is premature. (letter) *Am J Hum Gen* 1992 50:438-439

Wilfond BS, Nolan K. Developing the Clinical Application of Genetic Diagnosis: The Role of the NIDDK. (letter) *JAMA* 1994 271:1240

VIDEO PRODUCTION

"Between a Rock and a Hard Place: Values, Ethics and the Physician in Training"
American Medical Student Association 1985 (Writer and Executive Producer)

PRESENTATIONS (SINCE 1997)

CONGRESSIONAL TESTIMONY

May 1997 **"informed consent and participation of children in research"**
Subcommittee on human resources, Committee on Government Reform
and oversight, House of Representatives

INTERNATIONAL PRESENTATIONS

June 2002 **"Genetics Research"**
Ethical and Regulatory Aspects of Human Subjects Research
Seoul, Korea

- July 2001 **“Emerging ethical issues in pharmacogenomics”**
 Universidad Nova de Lisboa Portugal
- July 2000 **“Informed consent for in utero gene transfer research”**
 3rd Brazilian Congress on Bioethics. Porto Alegre, Brazil
- April 2000 **“Minimal Risk in Pediatric Research.”**
 National Conference on Minimal Risk. National Council on Ethics in
 Human Research. Ottawa, Ontario, Canada
- June 1999 **“Cystic fibrosis carrier testing and newborn screening:
 complementary or contradictory?”**
 (moderator) European Cystic Fibrosis Congress. Hague, Netherlands.
- Oct 1998 **“Cystic Fibrosis Newborn Screening”**
 (moderator) North American Cystic Fibrosis Conference
 Montreal, Quebec, Canada

CONFERENCES AND SPECIAL LECTURES

- Oct 2002 **“What work can informed consent do for patients and research
 subjects?”**
 (moderator) American Society for Bioethics and Humanities Annual
 Meeting. Baltimore, MD
- July 2002 **“Consent Monitoring”**
 Cystic Fibrosis Foundation Data Safety and Monitoring Committee Annual
 Meeting. Denver CO
- June 2002 **“Ethical Issue in cystic fibrosis newborn screening: From data to
 public health Policy”**
 Mid Atlantic CF Retreat, Villanova, PA
- June 2002 **“Ethical issues in pediatric research: Placebo controlled trials for
 gastroesophageal reflux”**
 Pediatric Advisory Sub committee, Anti-Infective Drugs Committee, FDA.
 Bethesda, MD
- May 2002 **“Ethical issues in Genetics Research”**
 American Thoracic Society Annual Meeting. Atlanta GA
- May 2002 **“The National Children’s Research Study”**
 Research with Children: The New Legal and Policy Landscape.
 University of Maryland School of Law, Baltimore MD

- March 2002 **“Cystic fibrosis newborn screening”**
American College of Medical Genetics Annual Meeting. New Orleans, LA
- Jan 2002 **“Screening and Carrier Testing for Genetic Diseases: Complementary or Contradictory?”**
Preventing Birth Defects and Infant Mortality: A Collaborative Approach to Prevention” (March of Dimes). Long Beach, CA
- Nov2001 **“Ethical issues about children with special needs: Decision-making by parents and providers”**
Pediatric Pulmonary Center Seminar. University of Arizona. Tucson, AZ
- Feb2002 **“Cystic fibrosis newborn screening”**
Department of Pediatrics Grand Rounds. Columbia University. New York, NY
- Oct 2001 **“Grant Writing Workshop”**
American Society for Bioethics and Humanites Annual Meeting. Nashville, TN
- Oct 2001 **“Beyond the family: genetics in the 21st Century”** (moderator)
American Society for Bioethics and Humanites Annual Meeting. Nashville, TN
- Oct 2001 **“The Invisible Hand in Clinical Research: The Study Coordinator's Critical Role in Human Subjects Protection”** (moderator)
American Society for Bioethics and Humanites Annual Meeting. Nashville, TN
- Sept 2001 **“End of Life in Cystic Fibrosis”**
Workshop on of life issues in genetics diseases. National Institute of Nursing Research. Bethesda, MD
- July 2001 **“A Framework for informed consent for clinical genetic tests”**
Secretary's Advisory Committee on Genetic Testing Meeting. Bethesda, MD
- April 2001 **“Ethical issues in pediatric research: Antimuscarinics to control the medical and psychosocial complications of drooling”**
Pediatric Advisory Sub committee, Anti-Infective Drugs Committee, FDA. Silver Spring. MD
- March 2001 **“Ethical issues in treating children with chronic disease.”**
Maryland Thoracic Society Annual Meeting. Baltimore MD

- March 2001 **“Emerging ethical issues in pharmacogenomics”**
Frontiers of Change: Navigating the Human Genome Map Conference.
University of Minnesota. Minneapolis, MN
- Feb 2001 **“Ethical issues in pediatric research”**
Pediatric Dietary Supplements Conference. National Institute of Child
Health and Development, Bethesda. MD
- Jan 2001 **“Carrier testing and newborn screening: Complementary or
Contradictory”**
Decade of ELSI Research Conference. NHGRI. Bethesda, MD
- Oct 2000 **“Subject selection: benefits, harms, and consent”**
American Society for Bioethics and Humanities Annual Meeting. Salt Lake
City, Utah
- Sept 2000 **“Bioethics: a new medical specialty”**
Benefis Health Care Perinatal Conference. Great Falls, Montana
- June 2000 **“Ethical Issue in Clinical Genetics”**
Ethics Committee Retreat, Boston Children’s Hospital, Boston MA
- June 2000 **“Bioethics: a new medical specialty”**
Anesthesia Grand Rounds, Boston Children’s Hospital, Boston MA
- June 2000 **“Ethical Issues in genetics research”**
Division of Medical Ethics, Harvard Medical School, Boston, MA
- March 2000 **“Informed consent for in utero gene transfer research”**
Genetics Short Course, University of Michigan, Ann Arbor MD
- Feb 2000 **“Informed consent for in utero gene transfer research”** Medical
Humanities Series. University of Maryland. Baltimore, MD
- Jan 2000 **“Prenatal and neonatal decision-making”**
Morristown Memorial Hospital, Morristown, NJ
- Dec 1999 **“Ethical issues in genetics research”**
Arizona Cancer Center, University of Arizona, Tucson, AZ
- Nov 1999 **“Risk in Pediatric Research”**
Pediatric Advisory Sub committee, Anti-Infective Drugs Committee, FDA.
Silver Spring. MD

- Oct 1999 **“Benefit and risk in pediatric research”**
American Society for Bioethics and Humanities Annual Meeting.
Philadelphia, PA. (moderator)
- Oct1999 **“Empirical Research on benefit in Research”**
American Society for Bioethics and Humanities Annual Meeting.
Philadelphia, PA.
- June 1999 **“Drawing Lines: Benefit, futility, and genetic testing”**
11th Annual Bioethics Summer Retreat. Hot Springs, VA
- May 1999 **“Informed consent for in utero gene transfer research”**
NIH Research Festival Mini-symposium. Bethesda, MD
- May 1999 **Genetic testing in children”**
State of the Art Symposium on the Human Genome Project, Pediatric
Academic Societies meeting. San Francisco, CA
- May 1999 **“Harm/benefit assessment”.**
Ethical Boundaries in Cancer Genetics. St. Jude's Children's Research
Hospital. Memphis, TN (moderator)
- May 1999 **“Informed consent for genetics research”**
Working Group on Communicating Informed Consent to Individuals Who
Are Deaf or Hard of Hearing. National Institute for Deafness and
Communication Disorders. Bethesda, MD
- May 1999 **“Ethical implications of the human genome project.”**
Genetics in the 21st Century: Crisis and Opportunity. Arizona Department
of Health Services, Phoenix, AZ
- March 1999 **“Developing genetic databases: Iceland”**
Emerging Issues in Genetics and the Law. Arizona State University.
Phoenix, AZ
- Jan1999 **“Informed consent and prenatal testing”**
Prenatal Gene Transfer: Scientific, Medical and Ethical Issues. Third Gene
therapy Policy Conference. NIH. Bethesda MD
- Dec 1998 **“Policy development of new genetic testing: implications for
hereditary hearing loss”**
Working Group on Considerations for Developing and Implementing
Genetic Diagnostic Tests for Hereditary Hearing Impairment and Other
Communication Disorders. National Institute for Deafness and
Communication Disorders Rockville. MD

- Oct 1998 **“Cystic Fibrosis Carrier Testing”**
National Coalition for Health Professional Education in Genetics,
Bethesda, MD
- May 1998 **“Ethical Issues with genetic testing”**
Keynote Address, Alpha 1 Antitrypsin Deficiency Annual Education
Meeting. Portland, OR
- Sept1997 **“Current Educational Materials for Cystic Fibrosis Genetic Testing”**
Follow-up Workshop to the Genetic Testing for Cystic Fibrosis Consensus
Development Conference, NHGRI. Bethesda, MD
- Sept 1997 **“Linkage and genetic testing”** Workshop on Ethical Issues on Umbilical
Cord Blood Banking. FDA/NHLBI/AABB. Arlington, VA
- Sept 1997 **“Carrier testing for cystic fibrosis: Abortion, public policy, and
disabilities”** Center for Bioethics, Case Western Reserve University.
Cleveland, OH
- Sept 1997 **“Presentation of information in cystic fibrosis screening
pamphlets,”** Genetics Grand Rounds, Case Western Reserve University.
Cleveland, OH
- June 1997 **“The NIH Consensus Conference on Genetic Testing for Cystic
Fibrosis”**
9th Annual Bioethics Retreat. Hilton Head, NC
- June 1997 **“Genetic Research in Children”**, Genetics Research and Human
Subjects: The Changing Landscape, Department of Energy/National
Institutes of Health. Bethesda, MD
- June 1997 **“Prenatal testing for cystic fibrosis: where to draw the line,”**
Workshop on Prenatal Diagnosis and Disability, Hastings Center. Briarcliff
Manor, NY
- April 1997 **“Normative Issues in developing public policy for cystic fibrosis
carrier testing”**
Cystic Fibrosis Genetic Testing Consensus Development Conference.NIH.
Bethesda, MD
- March 1997 **“Developing national policy related to genetic testing:
Hemachromatosis as a case study”**

Workshop on Iron Overload, Public Health, and Genetics, CDC. Atlanta, GA

Jan1997 **“Newborn screening for cystic Fibrosis: A paradigm for public health genetics”** National Policy Development for Genetic Technologies: Scientific, Political and Consumer Issue Policy Development, CDC. Atlanta, GA,

Jan1997 **“Human Genome Research”; “Research in Special Populations-Children”**
Challenging Issues for IRBs: Protection of Human Subjects Research, Arizona State University. Tempe, AZ (FDA/NIH sponsored conference)