

National Human Genome Research Institute

2003-2006

Head

Bioethics and Social Policy Unit
Behavioral and Social Research Branch

2003-2006

Deputy Director

Bioethics Core
Office of the Clinical Director

2000-2003

Head

Bioethics Research Section
Medical Genetics Branch

1998-2000

Co-Director

Office of Bioethics and Special Populations Research
Office of the Clinical Director

NIH Clinical Center

1998-2006

Head

Section on Ethics and Genetics
Department of Bioethics

Johns Hopkins University

2003-2006

Adjunct Associate Professor

Department of Health, Behavior and Society
Johns Hopkins Bloomberg School of Public Health

1998-2006

Visiting Associate Professor

Department of Pediatrics
Johns Hopkins University School of Medicine

University of Arizona

1998

Associate Professor (with tenure)

Department of Pediatrics
College of Medicine

1992-1998

Assistant Professor

Department of Pediatrics
College of Medicine

University of Wisconsin

1991-1992

Instructor

Department of Pediatrics
University of Wisconsin Medical School

HOSPITAL POSITIONS HELD

Current Medical Staff Appointments

2006 - present Seattle Children's Hospital
2006 - present University of Washington Medical Center
2006 - present Harborview Medical Center

Clinical Positions

2006-present **Director**
Treuman Katz Center for Pediatric Bioethics
Seattle Children's Hospital, Seattle, WA

1993-1998 **Director**
Infant Apnea/Bronchopulmonary Dysplasia Program
University Medical Center, Tucson, AZ

1997-1998 **Co-Director**
Cystic Fibrosis Center
University Medical Center, Tucson, AZ

1995-1997 **Associate Director**
Cystic Fibrosis Center
University Medical Center, Tucson, AZ

HONORS AND AWARDS

2006 **Distinguished Alumni Award**
University of Medicine and Dentistry of New Jersey

2004 **Alpha Omega Alpha**
New Jersey Medical School

2003 **Distinguished Alumni Award**
New Jersey Medical School

2001 **National Institutes of Health Award of Merit**
"Outstanding job of organizing a monthly ethics case conference
for the NHGRI Intramural Program"
National Human Genome Research Institute

1999 **National Institutes of Health Award of Merit**
"Outstanding efforts in establishing and organizing the operation
of an IRB for the NHGRI"
National Human Genome Research Institute

BOARD CERTIFICATION

1989-present American Board of Pediatrics #41759(2013)
1992-present Sub-Board of Pediatric Pulmonology #371 (2013)

CURRENT LICENCES TO PRACTICE

2006	State of Washington # MD00046647
1998	State of Maryland # D54108 (inactive)
1992	State of Arizona #20606

PROFESSIONAL ORGANIZATION RESPONSIBILITIES

American Academy of Pediatrics

1999-2000	Newborn Screening Taskforce
1996-2000	Committee on Bioethics
1997-1999	Working Group on Umbilical Cord Blood Banking (Co-Chair)

American Association of Bioethics and Humanities

2000	Annual Meeting Program Committee
1989-1990	Program Committee Student Interest Group (Society for Health and Human Values)

American Society of Human Genetics

1992-1995	Social Issues Committee
1992-1995	Subcommittee on genetic testing of children (Chair) Social Issues Committee

American Thoracic Society

1993-2005	Bioethics Task Force
2003-2004	Research Opportunities and Challenges in Pediatric Respiratory Medicine Writing Group
1998-2001	Genetics, psychosocial, economics, and ethics issues writing group. Taskforce on Standards of Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency

American Medical Student Association

1984-1985	Standing Committee on Bioethics (Founder and National Coordinator)
1983-1984	Board of Trustees

TEACHING RESPONSIBILITIES

Teaching Committee

2009-present	Admissions Committee MA Program Department of Bioethics and Humanities UW School of Medicine
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2007-2008 Masters Program Evaluation Committee
 Department of Bioethics and Humanities
 UW School of Medicine

2001-2006 Executive Committee
 Genetics Counseling Training Program
 National Human Genome Research Institute /Johns Hopkins University
 Bethesda/Baltimore, MD

1996-1998 Genetic Counseling Training Program Admissions Committee
 University of Arizona
 Tucson, AZ

Course Leadership

UNIVERSITY OF ARIZONA
 1995-1998

Course Director

“Medical Ethics”. Genetics 512. Required one credit for genetic counseling graduate students. Also taken by MPH Students and offered as noncredit elective for first and second year medical students.

1994-1998

Ethics Module Coordinator

“Social and Behavioral Sciences.” Medicine 505. 10 hour ethics module offered during the third semester of medical school.

Clinical Teaching

SEATTLE CHILDRENS HOSPITAL
 2006- present

Supervise Bioethics Fellows (Bioethics Consult Service)
 Supervise Pediatric Pulmonary Fellows and Pediatric Residents
 (Outpatient Clinic and Inpatient Consults)

NIH CLINICAL CENTER
 1998-2006

Supervise Bioethics Fellows (Bioethics Consult Service)

JOHNS HOPKINS UNIVERSITY
 1998-2006

Supervise Pediatric Pulmonary Fellows (Outpatient Clinic)

UNIVERSITY OF ARIZONA
 1992-1998

Supervise Pediatric Pulmonary Fellows, Pediatric Residents, and Medical Students (Inpatient and Outpatient)

Trainees

A. DISSERTATION COMMITTEES

- 2008 Aaron Goldenberg (PhD)
“Newborn screening and public policy”
Department of Bioethics
Case-Western Reserve University
- 2007 Rachel Jacobson (MSc)
“Moral Value Conflicts Among Genetic Counselors”
Department of Health Behavior and Society
Johns Hopkins School of Public Health
- 2005 Ingrid Burger (MD/PhD)
“Radiologist attitudes about whole body CT Scanning”
Program in Law, Society and Ethics
Johns Hopkins School of Public Health
- 2006 Kate Reed (MSc) (Thesis Advisor)
“Genetic Susceptibility Information as a Cue to Action: Impact of Risk
Information Source on Perceived Motivation for Behavior Change”
Department of Health Behavior and Society
Johns Hopkins School of Public Health
- 2006 Merideth Weaver (MSc)
“Genetic counselors engaging in advocacy”
Department of Health Behavior and Society
Johns Hopkins School of Public Health
- 2005 Danielle Dong (MSc) (Thesis Advisor)
“Causal Attributions and Perceived Personal Control in Caregivers of Children
with an Autistic Spectrum Disorder”
Department of Health Behavior and Society
Johns Hopkins School of Public Health
- 2004 Delphine Blain (MSc) (Thesis Advisor)
“Adoption of the 2001 ACOG Guidelines for Cystic Fibrosis Carrier Screening
by Obstetricians”
Department of Health Behavior and Society
Johns Hopkins School of Public Health
- 2003 Elizabeth Lardy (MSc)
“Genetic Counselors’ Descriptions of Down Syndrome”
Department of Health Behavior and Society
Johns Hopkins School of Public Health
- 2001 Lois Loescher (PhD)
“Perceived Risk of inherited susceptibility to cancer”
College of Nursing
University of Arizona

1999 Sara Hull (PhD)
“Sickle Cell Disease, Cystic Fibrosis, And Reproduction: A Qualitative Study
of Affected Adults and Health Care Provider Perspectives”
Program in Law, Society and Ethics
Johns Hopkins School of Public Health

1997 Greg Loeben (PhD)
“Medical Futility and the Goals of Medicine”
Department of Philosophy
University of Arizona

B.POST DOCTORAL RESEARCH TRAINEES

2006-2009 Doug Opel MD

2003-2005 Vardit Ravitsky PhD

1999-2001 Carol Fruend PhD

EDITORIAL RESPONSIBILITIES

2002-2009 **Editorial Board**
American Journal of Bioethics

1995-1999 **Editorial Board**
American Journal of Medical Genetics

SPECIAL NATIONAL RESPONPONSIBILITIES

National Institutes of Health

2009- present Operations Group
Clinical Research Ethics Key Function Committee
Clinical and Translational Science Award Consortium
National Center for Research Resources

2009- present Research Ethics Consultation Committee (Chair)
Clinical Research Ethics Key Function Committee
Clinical and Translational Science Award Consortium
National Center for Research Resources

2008- present Clinical Research Ethics Key Function Committee
Clinical and Translational Science Award Consortium
National Center for Research Resources

2008- present Pediatric Research Ethics Working Group
Clinical and Translational Science Award Consortium
National Center for Research Resources

2008- present	Research Ethics Consultation Committee Clinical Research Ethics Key Function Committee Clinical and Translational Science Award Consortium National Center for Research Resources
2008- present	National Children's Study Advisory Committee National Institute of Child Health and Development
2007-present	Special Emphasis Panel (ad hoc study section) Center for Scientific Review
2007-present	Data and Safety Monitoring Board Childhood Adenoidectomy Tonsillectomy Study National Heart Lung and Blood Institute
2001-present	Data and Safety Monitoring Board Childhood Asthma Research and Education Network National Heart Lung and Blood Institute
2005-2006	Medical Sequencing Working Group (ELSI Committee) National Human Genome Research Institute
2001-2004	Ethics Working Group (Co-Chair) National Children's Study National Institute of Child Health and Development
2003-2004	USIDNet Repository Committee National Institute of Allergy, Immunology, and Infectious Disease
2002-2004	Working Group on Bioethics Literature National Library of Medicine
2002	Study Section Member (Ad Hoc) National Heart Lung and Blood Institute
1998-1999	Working Group on Cystic Fibrosis Educational Materials National Human Genome Research Institute
1995-1998	Cancer Genetic Studies Consortium (Consultant) National Human Genome Research Institute
1996	Consensus Development Conference for Genetic Testing for Cystic Fibrosis Planning Committee Office of Medical Applications of Research
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

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

Food and Drug Administration

2008-present Pediatric Ethics Subcommittee, Pediatric Advisory Committee

1999-2006 Pediatric Ethics Working Group

2003-2004 Ethics Working Group
Newborn Drug Development Initiative
(with National Institute of Child Health and Development)

1999-2003 Pediatric Advisory Committee of the Anti-Infective Drugs Advisory
Committee (consultant)

Center for Disease Control and Prevention

2004 Cystic Fibrosis Newborn Screening Writing Committee

2003 Cystic Fibrosis Newborn Screening Planning Committee

Health Services Resource Administration

2001 Study Section Member
Newborn Screening Grant Review Committee

Department of Health and Human Services

2001-2002 Informed Consent/IRB Working Group (**Co-chair**)
Secretary's Advisory Committee on Genetic Testing

Cystic Fibrosis Foundation

2003-present Gene Modifier Scientific Advisory Committee

2000-present Data Safety and Monitoring Committee

2004 Planning Committee
Implementation of CF Newborn Screening Workshop

March of Dimes

2007-present Bioethics Advisory Committee

SPECIAL LOCAL RESPONSIBILITIES

Seattle Children's

2008-present Data Utilization Committee
Global Alliance for the Prevention of Prematurity and Stillbirths

2007-present Board of Trustees Quality Committee

2007-present	Center Director Advisory Committee Seattle Children's Research Institute
2007-present	Steering Committee Center for Clinical and Translational Research
2006-present	Bioethics Consult Service
2007-2008	Diversity Center Director Search Committee

Department of Bioethics and Humanities, University of Washington

2008-present	Faculty Search Committee
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Institute for Translational Health Sciences

2009-present	ITHS Steering Committee (chair)
2008-present	ITHS Small Grant Review Committee
2007-present	ITHS Leadership Committee
2007-present	Regulatory Support and Bioethics Core (co director)
2007-present	Research Bioethics Consult Service (director)

Institute for Public Health Genetics, School of Public Health and Community Medicine, University of Washington

2007-present	Internal Advisory Committee
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National Institutes of Health

2005-2006	Human Subjects Research Advisory Committee Division of Intramural Research
2005-2006	Institutional Review Board (chair) National Human Genome Research Institute
2000-2006	Committee on Scientific Conduct and Ethics Division of Intramural Research
1998 -2006	Ethics Committee NIH Clinical Center
1998-2006	Bioethics Consultation Service Department of Bioethics NIH Clinical Center
1998-2005	Institutional Review Board (Associate chair) National Human Genome Research Institute

2000-2002 Institutional Review Board
National Institute of Child Health and Development

1999- 2000 Institutional Review Board
National Heart Lung and Blood Institute

Arizona

1998 Ethics Committee (Chair)
University Medical Center

1997-1998 Ethics Committee
Tucson Medical Center

1993-1998 Human Subjects Committee
University of Arizona

1992-1998 Ethics Committee
University Medical Center

Wisconsin

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

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

1988-1992 Ethics Committee
Meriter Hospital

Other Local Responsibilities

2003-2006 **Member**
RJ Fellowship Advisory Board
Muhlenberg College

2003-2005 **Member**
Bioethics Advisory Board
Wyeth Pharmaceuticals

RESEARCH FUNDING

Active

Institute of Translational Health Sciences (1 UL1 RR 025014-01 NIH/NCRR)

9/17/07-5/31/12

Co-Director, Regulatory Support and Bioethics Core (15%)

Mary L. Disis PI \$6,513,229

"Development of the First Test for Common Cancer Risk in the General Population"

The Doris Duke Charitable Foundation

10/05 to 9/2010

Key Investigator (5%)

Andrew Feinberg, Johns Hopkins University PI \$2,083,335

Past

"The Ethical and Policy Implications of Growth Attenuation in Children with Profound Developmental Disabilities" Greenwall Foundation-Bioethics Award Program

1/08 to 12/2008

Principal Investigator (2.5%) \$40,000

"The Ethical and Policy Implications of Growth Attenuation in Children with Profound Developmental Disabilities" Walter Chapman Simpson Center for the Humanities

1/08 to 2/2000

Principal Investigator \$17,000

"Social Construction of Benefit in Gene Transfer Research (R01HG 002087)

National Human Genome Research Institute

9/1999-12/2006

Co-investigator (no direct support as NHGRI employee) (10%)

PI-Gail Henderson UNC-Chapel Hill \$668,682

"Genetic Screening in Primary Care: Ethics and Policy" (R29 HS08570)

Agency for Health Care Policy and Research

1994-1998

Principal Investigator (65%) \$304,230

"Genetic testing for Cancer"

Udall Center for Studies in Public Policy, University of Arizona

1996

Udall Center Faculty Fellowship

"A Phase IV, Multicenter, Study to Monitor the Long-Term Safety and Efficacy of Pulmozyme (dornase alfa) in Cystic Fibrosis Patients Who Participated in a Phase III Study"

Genentech

1994-1996

Site Investigator \$23,400

"Epidemiologic Study of Cystic Fibrosis: A Multicenter, Longitudinal Follow-Up Study of Patients With Cystic Fibrosis for Monitoring Pulmonary Function, Pulmonary Exacerbations, and the Safety of Long-Term Treatment with Pulmozyme (dornase alfa)" Genentech:
1994-1998

Site Investigator \$41,250

"Cystic Fibrosis Heterozygote Detection: Introduction of Genetic Testing into Clinical Practice" Ethical, Legal and Social Implications (ELSI) Program. National Center for Human Genome Research

1990

Principal Investigator \$6,000 (contract)

"Clinical Fellowship Award"

Cystic Fibrosis Foundation

1989-1990

Principal Investigator \$31,000

"Between a Rock and a Hard Place: Values, Ethics and the Physician in Training"

1985

Squibb Co. \$8,500

Writer and Executive Producer (video production)

J Sachs PI

PUBLICATIONS

A REFEERED JOURNAL ARTICLES

1. Wilfond BS and Fost N. The CF gene: Medical and social implications of heterozygote detection. *JAMA* 1990 263:2777-2783
2. 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
3. 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
4. Lippman A, Wilfond BS. "Twice-told tales: stories about genetic disorders. *Am J Hum Gen* 1992 51:36-37
5. 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
6. Wilfond BS, Nolan K. National policy development for the clinical application of genetic diagnostic technologies: lessons for cystic fibrosis. *JAMA* 1993 270:2948-2954
7. 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

8. 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
9. Wilfond BS. Screening policy for cystic fibrosis: The role of evidence. *Hastings Center Report* 1995 25:S21-S23
10. 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
11. 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
12. 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 taskforce on informed consent of the NIH Cancer Genetic Studies Consortium. *JAMA* 1997 277:1467-1474
13. 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
14. Loeben G, Wilfond BS. What we should learn about communication from the placebo effect. *Ethics and Behavior* 1998 8:89-98
15. Loeben G, Marteau MM, Wilfond BS. Mixed Messages: Presentation of information in cystic fibrosis screening pamphlets. *Am J Hum Genet.* 1998 63:1182-1190
16. Ozdemer A, Costentino C, Siwik SA, Wilfond BS. Orange Seed Aspiration. *Arch Pediatr Adolesc Med* 1998 152:921-922
17. 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
18. 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
19. 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

20. 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
21. 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
22. 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
23. Gooding H, Wilfond B, Boehm K, and Biesecker BB. Unintended Messages: The ethics of teaching genetics dilemmas. *Hastings Center Report* 2002 32:37-9.
24. 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
25. Freund C and Wilfond BS. Emerging ethical issues in pharmacogenomics. *American Journal of Pharmacogenomics* 2002 2:273-281
26. 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
27. Gollust SE, Hull SC, Wilfond BS. Limitations of Direct-to-Consumer Advertising for Clinical Genetic Testing. *JAMA*. 2002 288:1762-7
28. 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 30:411-9
29. Horng 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 347:2134-40
30. Wilfond BS, Geller G, Lerman C, Audrain-McGovern J, and Shields AE. Ethical issues in conducting behavioral genetics research: the case of smoking prevention trials among adolescents. *Journal of Health Care Law & Policy* 2002 6:73-88
31. Miler F, Wendler D, and Wilfond B. When do the federal regulations allow placebo controlled trials in children. *J Peds* 2003 142:102-7
32. Koogler T, Wilfond B and Ross LF. Lethal language, lethal decisions. *Hastings Center Report* 2003 33:37-41
33. Gollust S, Wilfond BS, and Hull SC. Direct to consumer sales of genetic services over the Internet. *Genetics in Medicine* 2003 5:332-337

34. Wendler D, Shah S, Whittle A, and Wilfond B. Non-beneficial research in individuals who cannot consent: Is it ethically better to enroll healthy or affected individuals? *IRB:Ethics & Human Research* 2003 24 (4):1-4
35. Churchill LR, Nelson DK, Henderson GE, King NMP, Davis AM, Leahey E, Wilfond BS. Assessing benefits in clinical research: Why diversity in benefit assessment can be risky *IRB:Ethics & Human Research* 2003 25 (3):1-3
36. Coffey MJ, Wilfond B and Ross LF. Ethical assessment of clinical asthma trials including children subjects. *Pediatrics* 2004 113:87-94
37. Shah S, Whittle A, Wilfond B, Gensler G, Wendler D. How do institutional review boards apply the federal risk and benefit standards for pediatric research. *JAMA* 2004 291:476-482
38. Freund CL, Clayton EW, and Wilfond BS. Natural Settings Trials: Improving the introduction of new clinical genetic tests. *Journal of Law Medicine and Ethics* 2004 32:106-110
39. Whittle A, Shah S, Wilfond B, Gensler G, Wendler D. Institutional review practices regarding assent in pediatric research. *Pediatrics* 2004 113:1747-1752
40. Hull SC, Gooding H, Klein AP, Washauer-Baker E, Metosky S, and Wilfond BS. Genetics research involving human biological materials: A need to tailor consent forms *IRB:Ethics & Human Research* 2004 26(3):1-7
41. Taylor H and Wilfond B. Ethical Issues in Newborn Screening Research: Lessons from the Wisconsin Cystic Fibrosis Trial. *J Peds* 2004 145:292-6.
42. Henderson GE, Davis AM, King NM, Easter MM, Zimmer CR, Rothschild BB, Wilfond BS, Nelson DK, Churchill LR. Uncertain benefit: investigators' views and communications in early phase gene transfer trials. *Mol Ther* 2004 10: 225-31.
43. Hull SC, Glanz K, Steffan A, and Wilfond BS. Recruitment approaches for family studies. *IRB:Ethics & Human Research* 2004 26:12-18
44. King NMP, Henderson GE, Churchill LR, Davis AM, Hull SC, Nelson DK, Parham-Vetter PC, Rothschild BR, Easter MM, and Wilfond BS. Consent forms and the therapeutic misconception: The example of gene transfer research. *IRB:Ethics & Human Research* 2005 27:1-9
45. Leib JR, Gollust SE, Hull SC, and Wilfond BS. Carrier Screening Panels for Ashkenazi Jews: Is More Better? *Genetics in Medicine* 2005 7:185-190
46. Wilfond BS and Gollust SE. Policy issues for expanding newborn screening programs: The cystic fibrosis newborn screening experience in the United States. *J Peds* 2005 46:668-74
47. Wilfond BS, Ravitsky, V. On the Proliferation of Bioethics Sub-Disciplines: Do We Really Need "Genethics" and "Neuroethics"? *American Journal of Bioethics*. 2005 5(2): 20-21

48. Wilfond BS, Parad RB, and Fost N. Balancing benefits and risks for cystic fibrosis newborn screening; Implications for policy decisions. *J Peds* 2005 147(3S):S109-S113
49. Henderson GE, Easter MM, Zimmer C, King NMP, Davis AM, Rothschild BB, Churchill LR, Wilfond BS and Nelson DK. Therapeutic Misconception in Early Phase Gene Transfer Trials. *Social Science in Medicine* 2006 62:239-53
50. Grosse SD, Boyle CA, Kenneson A, Khoury MJ, and Wilfond BS. From Public Health Emergency to Public Health Service: The Implications of Evolving Criteria for Newborn Screening Panels. *Pediatrics* 2006 117:923-9.
51. Loud JT, Weissman N, Giusti R, Wilfond BS, Burke W, and Greene MH. Deliberate Deceit of Family Members: A Challenge to Providers of Clinical Genetics Services. *Journal of Clinical Oncology* 2006 24:1643-6.
52. Bookman EB, Langehorne AA, Eckfeldt JH, Glass KC, Jarvik GP, Klag M, Koski G, Motulsky A, Wilfond B, Manolio TA, Fabsitz RR, Luepker RV. Reporting genetic results in research studies: Summary and recommendations of an NHLBI working group. *Am J Med Genet* 2006 140A:1033-1040
53. Botkin JR, Clayton EW, Fost, NC, Burke W, Murray TH, Baily MA, Wilfond BS, Al Berg A, Ross L. Newborn Screening Technology: Proceed with Caution. *Pediatrics* 2006 117:1793-1799
54. Ravitsky V, Wilfond BS. Disclosing Individual genetic results to research participants. *American Journal of Bioethics*. 2006 6(6):8-17
55. Wade CH, Wilfond BS. Ethical and clinical practice dilemmas for genetic counselors associated with direct-to-consumer marketing of genetic tests. *Am J Med Genet*. 2006 142(4):284-92
56. Comeau AM, Accurso FJ, White TB, Campbell PW 3rd, Hoffman G, Parad RB, Wilfond BS, Rosenfeld M, Sontag MK, Massie J, Farrell PM, O'Sullivan BP. Guidelines for implementation of cystic fibrosis newborn screening programs: Cystic Fibrosis Foundation workshop report. *Pediatrics*. 2007 Feb;119:e495-518
57. Myers RE, Weinberg DS, Manne SL, Sifri R, Cocroft J, Kash K, Wilfond B. Genetic and environmental risk assessment for colorectal cancer risk in primary care practice settings: a pilot study. *Genet Med*. 2007 9(6):378-384.
58. Henderson GE, Churchill LR, Davis AM, Easter MM, Grady C, Joffe S, Nancy Kass N, King NMP, Lidz CW, Miller FG, Nelson DK, Peppercorn J, Bluestone Rothschild B, Sankar P, Wilfond BS and Zimmer CR. Defining the Therapeutic Misconception: Problems and Prospects. *PLOS Medicine* 2007 4(11):e324
59. Wilfond BS. Ethical considerations about observational research in children. *J of Trauma* 2007;63(6 Suppl):S146-51

60. Tarini BA, Burke W, Scott CR, Wilfond BS. Waiving informed consent in newborn screening research: balancing social value and respect. *Am J Med Genet C*. 2008 148(1):23-30
61. Kelley M, Fryer-Edwards K, Fullerton SM, Gallagher T, Wilfond B. Sharing Data and Experience: Using the CTSA "Moral Community" to Improve Research Ethics Consultation. *Amer J of Bioethics*, 2008 (3):37-9
62. Wilfond BS, Carpenter KJ. Incidental Findings in Pediatric Research. *Am J Law Med Ethics*. 2008 36:332-340
63. Wolf SM, Lawrenz FP, Nelson CA, Kahn JP, Cho MK, Clayton EW, Fletcher JG, Georgieff MK, Hammerschmidt D, Hudson K, Illes J, Kapur V, Keane MA, Koenig BA, Leroy BS, McFarland EG, Paradise J, Parker LS, Terry SF, Van Ness B, Wilfond BS. Managing incidental findings in human subjects research: analysis and recommendations. *J Law Med Ethics*. 2008 36: 219-48.
64. Wilfond BS and Ross LF. From Genetics to Genomics: Ethics, Policy, and Parental Decision-Making *J Peds Psychol* 2008 (Epub)
65. Denny CC, Wilfond BS, Peters JA, Neelam G, Alter BP. All in the Family: Disclosure of "Unwanted" Information to an Adolescent to Benefit a Relative. *Am J Med Genet A* 2008 146A(21):2719-24.)
66. Hull SC, Sharp RR, Botkin JR, Brown MA, Hughes, M, Schwinn, D, Sankar P, Sugarman, J, Bolcic-Jankovic D, Clarridge BR, Wilfond, BS. Patients' views on identifiability of samples and informed consent for genetic research. *Amer J of Bioethics*, 2008. 8(10):62-70

B. PROFESSIONAL ORGANIZATION POLICY PAPERS

1. 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
2. American Thoracic Society Board of Directors. Fair Allocation of Intensive Care Unit Resources. *Am J Respir Crit Care Med* 1997; 156:1282-1301
3. American Academy of Pediatrics, Committee on Bioethics. Female Genital Mutilation. *Pediatrics* 1998; 102:153-156
4. American Academy of Pediatrics, Committee on Bioethics. Sterilization of Minors with Developmental Disabilities. *Pediatrics* 1999; 104: 337-340
5. American Academy of Pediatrics, Committee on Bioethics. Appropriate Boundaries in the Pediatrician-Family-Patient Relationship. *Pediatrics* 1999; 104:334-336
6. American Academy of Pediatrics, Working Group on Cord Blood Banking. Cord Blood Banking for Potential Future Transplantation: Subject Review. *Pediatrics* 1999; 104:116-118 (Co Chair)

7. 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
8. American Academy of Pediatrics, Newborn Screening Taskforce. Newborn Screening: A Blueprint for the Future. *Pediatrics* 2000; 106:389-427
9. American Academy of Pediatrics, Committee on Bioethics. Palliative Care for Children. *Pediatrics* 2000; 106:351-357
10. American Academy of Pediatrics, Committee on School Health and Committee on Bioethics. Do Not Resuscitate Orders in Schools. *Pediatrics* 2000. 105: 878-879
11. 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
12. American Academy of Pediatrics, Committee on Bioethics. Institutional Ethics Committees *Pediatrics* 2001. 107:205-209
13. American Thoracic Society/European Respiratory Society Statement: Standards for the Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency. *Am J Respir Crit Care Med*. 2003.168:818-900.
14. Grosse SD, Boyle CA, Botkin JR, Comeau AM, Kharrazi M, Rosenfeld M, Wilfond BS. (CDC Workshop Writing Group). Newborn Screening for Cystic Fibrosis: Evaluation of Benefits and Risks and Recommendations for State Newborn Screening Programs. *MMWR* 2004 53 (RR-13): 1-35
15. Lands LC, Allen J, Cloutier M, Leigh M, McColley S, Murphy T, Wilfond B; Pediatric Assembly of American Thoracic Society Subcommittee. ATS Consensus Statement: research opportunities and challenges in pediatric pulmonology. *Am J Respir Crit Care Med*. 2005;172:776-80.
16. Lanken PN, Terry PB, Delisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE, Levy M, Mularski RA, Osborne ML, Prendergast TJ, Ricker G, Sibbald WJ, Wilfond B, Yankaskas JR; ATS End-of-Life Care Task Force. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med*. 2008 Apr 15;177(8):912-27.

C. BOOK CHAPTERS

1. 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
2. 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
3. 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

4. Wilfond BS. *Genetic Testing* in Sugarman J, ed. Ethics in Primary Care. McGraw-Hill, New York, NY 2000:67-77
5. Gollust S and Wilfond B. *Population carrier screening: psychological impact* Nature Encyclopedia of the Human Genome. Nature Publishing Group New York NY 2003: 618-621 (vol 4)
6. Wilfond B and Candotti F. *When Eligibility Criteria Clash with Personal Treatment Choice: A Dilemma of Clinical Research* in Kodish E, ed. Ethics and Research in Children. Oxford University Press, New York, NY 2005:310-322

D. VIDEO PRODUCTION

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

E. LETTERS AND COMMENTARIES

1. Wilfond BS, Nolan K. Developing the Clinical Application of Genetic Diagnosis: The Role of the NIDDK. (letter) *JAMA* 1994 271:1240
2. 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
3. Biesecker L, Wilfond B. Generic Consent for Genetic Screening. (letter) *NEJM* 1994 331:1024
4. Wilfond BS, Genetic Testing in Children.(commentary) *Perspectives in Genetic Counseling* 1995 17:9
5. Wilfond BS. Genetic testing should be deferred until adulthood. (commentary) *AAP News*. November 1996
6. Wilfond BS. Genetic testing, not cloning, is worrisome. (Guest commentary) *Arizona Daily Star*. March 1997
7. 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.
8. Gollust SE, Hull SC, and Wilfond B. Direct-to-Consumer Advertising of Genetic Testing *JAMA*. 2003; 289:46.
9. Wilfond, BS. The Ashley Case: The Public Response and Policy Implications. *Hasting Center Report* 2007 37(5)12-13 (Policy and Politics Commentary)
10. Hull SC, Wilfond BS. What does it mean to be identifiable? *Am J Bioeth*. 2008 8(10):W7-8

11. Wilfond BS. The Genetic Information Nondiscrimination Act: fear factor or fantasy island? *Hastings Cent Rep.* 2008 38(6):11-2. (Policy and Politics Commentary)
12. Opel DJ, Wilfond BS. Cosmetic surgery in children with cognitive disabilities: who benefits? Who decides? *Hastings Center Report.* 2009 39(1):19-21

SELECTED 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

Feb 2008 **“Resolving conflicts in the ICU”** Pediatric Critical Care Symposium
 Wistler, BC, Canada

Nov 2006 **“Ethical issues in pediatric research”, “Ethical issues in genetics research”**
 NIH Fogarty Center Latin American Seminar on Research Ethics, Buenos Aires, Argentina

March 2006 **“Genetics research”, “Ethics and pediatrics”, “Ethics and genetics”**
“End of life decision-making” Third Latin American Conference on Bioethical Issues in Research and Clinical Practice, US Naval Research Center, Lima, Peru

May 2004 **“Empirical research on informed consent”, “Genetics research”**
 Ethical and Regulatory Aspects of Human Subjects Research. University of Sao Paulo School of Medicine, Sao Paulo, Brazil

Oct 2003 **“Bioethics and Data Monitoring Committees”** (moderator) American Society of Bioethics and Humanities, Montreal, Canada

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

July 2001 **“Emerging ethical issues in pharmacogenomics”** Universidade 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

FEDERALLY SPONSORED COFERENCES

- March 2009 **“From Public health emergency to public health service: ethical and policy issues in expanding newborn screening”** Early Detection of Neuromuscular Diseases. NICHD. Bethesda, MD
- Nov 2008 **“Prenatal testing for CMV: Lesson from cystic fibrosis”** Congenital Cytomegalovirus Conference. Center for Disease Control and Prevention. Atlanta GA
- June 2008 **“Ethical considerations in preventing preterm births”** The Surgeon General’s Conference on the Prevention of Preterm Birth. Bethesda, MD
- March 2007 **“Ethical issues in Pediatric Outcomes Research”** Pediatric Trauma Care: A workshop to develop a national study on the costs and outcomes from pediatric trauma. Washington DC
- Jan 2006 **“The Participation of Children in Genetics Research”** National Children’s Study Federal Advisory Committee Meeting Gaithersburg, MD
- Jan 2006 **“Health Services Working Group Report”** Multiplex Initiative Working Group. NHGRI. Bethesda, MD
- Sept 2005 **“Risk Communication and Behavioral Change”** Multiplex Initiative Working Group. NHGRI Philadelphia, PA
- July 2004 **“Ethical Issues in Disclosing Genetics Research Results”** NHLBI Working Group on Research Results. Bethesda MD
- May 2004 **“Disclosure of Research findings and the National Childrens’ study”** Committee on Ethical Issues in Housing-Related Health Hazard Research Involving Children, Youth, and Families. IOM. Washington, DC
- Nov 2003 **“Overview of Cystic Fibrosis Newborn Screening Approaches”** Newborn Screening for Cystic Fibrosis Workshop, CDC. Atlanta, GA
- Sept 2003 **“Ethical Issues in Pediatrics Research”** Pediatric Research Colloquia, NICHD. Bethesda, MD
- June 2003 **“Ethical Issues in Pediatric Longitudinal Research: Looking Back, thinking forward”** (Co chair) National Children’s Study Workshop, NICHD. Bethesda, MD
- March 2003 **“The National Children’s Study: ethical issues in longitudinal research”** Committee on Clinical Research Involving Children IOM. Irvine, CA
- June 2002 **“Ethical issues in pediatric research: Placebo controlled trials for gastroesophageal reflux”** Pediatric Advisory Sub Committee, Anti-Infective Drugs Committee, FDA. Bethesda, MD

- Sept 2001 **“End of Life in Cystic Fibrosis”** Workshop on End of Life Issues in Genetics Diseases NINR. Bethesda, MD
- July 2001 **“A Framework for informed consent for clinical genetic tests”**
Secretary’s Advisory Committee on Genetic Testing. 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
- Feb 2001 **“Ethical issues in pediatric research”** Pediatric Dietary Supplements Conference. NICHD. Bethesda, MD
- Jan 2001 **“Carrier testing and newborn screening: Complementary or Contradictory”**
Decade of ELSI Research Conference, NHGRI. Bethesda, MD
- Nov 1999 **“Risk in Pediatric Research”** Pediatric Advisory Sub Committee, Anti-Infective Drugs Committee FDA. Silver Spring, MD
- May 1999 **“Informed consent for genetics research”** Working Group on Communicating Informed Consent to Individuals Who Are Deaf or Hard of Hearing. NIDCD. Bethesda, MD
- Jan 1999 **“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. NIDCD. Rockville, MD
- Sept 1997 **“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 of information and genetic testing”** Workshop on Ethical Issues on Umbilical Cord Blood Banking. FDA/NHLBI/AABB. Arlington, VA
- 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: Hemochromatosis 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 Issues in Policy Development. CDC. Atlanta, GA
- NATIONAL PROFESSIONAL MEETINGS
- Oct 2008 **“Ethical Considerations in Research Recruitment”** North American Cystic Fibrosis Conference. Orlando FL
- Oct 2008 **“Bioethics Consultations and the CTSA: Using a computer application to facilitate quality improvement and data sharing”** American Society of Bioethics and Humanities. Cleveland OH
- June 2008 **“Dennis Lindberg’s Refusal of Treatment: thoughts on the Authority of Adolescent Decisions”** 20th Annual Bioethics Retreat. Santa Rosa CA
- May 2008 **“Genetic Testing and Research in Children” Ethical and Policy Implications.** Translating "ELSI": Ethical, Legal and Social Implications of Genomics. Cleveland OH
- May 2008 **When Parents Request Medical Care that Providers Resist: Ethics and Law in Futility Disputes** (moderator) Pediatric Academic Society Annual Meeting. Honolulu, HI
- Oct 2007 **“Ashley Revisited: Is Growth Attenuation Ever Justified in a Profoundly Disabled Child?”** (Moderator) ”American Society of Bioethics and Humanities Annual Meeting Washington, DC; October 2007
- Oct 2007 **“Family perspectives on returning research results”** (moderator) ASCO/COG Symposium on ethical considerations in disclosing study results to research participants. Denver CO
- Oct 2006 **“Pediatric biobanks and the limits of parental permission”** American Society of Bioethics and Humanities Annual Meeting. Denver, CO
- Oct 2006 **“Pediatric Biobanks”** ASCO/COG Symposium on ethical issues in genetic research on children with cancer. Children’s Oncology Group Meeting. Los Angeles, CA
- Oct 2005 **“Ethical and policy implications of the \$1000 Genome** (moderator) American Society for Bioethics and Humanities Annual Meeting Philadelphia, PA
- Oct 2005 **“Conflicts of interest and industry sponsorship of continuing medical education: The case of pediatric depression”** American Academy of Pediatrics National Conference and Exhibition. Washington, DC
- March 2005 **“Bioethics: From the Margin to the Mainstream”** American Medical Student Association National Convention. Arlington, VA

- Oct 2004 **“Cystic Fibrosis newborn screening: the good, the bad, and the ugly”**
American Society for Bioethics and Humanities Annual Meeting Philadelphia, PA
- Oct 2004 **“Recruitment in clinical research: Balancing advocacies”**
North American Cystic Fibrosis Conference. St Louis, MO
- June 2004 **“Public Health Meets Genetics”** 16th Annual Bioethics Summer Retreat.
Wintergreen, VA
- Dec 2003 **“Enrolling pregnant adolescents in research: Multi-IRB review of the
National Childrens’ Study”** Applied Research Ethics National Association
Annual Meeting. Washington, DC.
- Oct 2003 **“Decision monitoring for adolescents in gene transfer research”** North
American Cystic Fibrosis Conference. Anaheim, CA
- Dec 2002 **“Ethical issues in pharmacogenomics”** Joseph A Oddis Ethics Colloquium.
American Society of Health Systems Pharmacists Midyear Meeting. Atlanta GA
- Oct 2002 **“What work can informed consent do for patients and research subjects?”**
(moderator) American Society for Bioethics and Humanities Annual Meeting.
Baltimore, MD
- May 2002 **“Ethical issues in Genetics Research”** American Thoracic Society Annual
Meeting. Atlanta, GA
- March 2002 **“Cystic fibrosis newborn screening”** American College of Medical Genetics
Annual Meeting. New Orleans, LA
- Oct 2001 **“Grant Writing Workshop”** American Society for Bioethics and Humanities
Annual Meeting. Nashville, TN
- Oct 2001 **“Beyond the family: genetics in the 21st Century”** (moderator)
American Society for Bioethics and Humanities 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 Humanities Annual Meeting.
Nashville, TN
- Oct 2000 **“Subject selection: benefits, harms, and consent”** American Society for
Bioethics and Humanities Annual Meeting. Salt Lake City, Utah
- Oct 1999 **“Benefit and risk in pediatric research”** American Society for Bioethics and
Humanities Annual Meeting. Philadelphia, PA
- Oct 1999 **“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 **“Genetic testing in children”** State of the Art Symposium on the Human Genome Project. Pediatric Academic Societies Meeting. San Francisco, CA
- June 1997 **“The NIH Consensus Conference on Genetic Testing for Cystic Fibrosis”** 9th Annual Bioethics Retreat. Hilton Head, NC
- INVITED CONFERENCE PRESENTATIONS(selected, since 2000)
- Jan 2009 **“Evaluating Growth Attenuation in Children with Profound Disabilities: Interests of the Child, Family Decision-Making and Community Concerns”** (Moderator) University of Washington, Seattle WA
- Nov 2008 **“Ethical issues in Genetic Research”** Ethical and Regulatory Issues in Human Subjects Research, National Institutes of Health Clinical Center. Bethesda MD
- Nov 2008 **“Bioethical Issues in Prenatal Diagnosis and Therapy”** Prenatal Diagnosis: Outcomes and Transition to Pediatric Care. Seattle Children’s Hospital. Seattle WA
- July 2008 **“Tale of two cities: Genomics, ethics, and parental decision-making?”** Predicting our Future: Genetic Testing in Children and their Families. 4th Annual Treuman Katz Pediatric Bioethics Conference. Seattle WA.
- July 2007 **“Show Me the Money: Financial Considerations in Responding to Parental Wishes”** Navigating conflicts when parents and providers disagree about health care” 3rd Annual Pediatric Bioethics Conference. Treuman Katz Center for Pediatric Bioethics. Seattle, WA
- May 2007 **“The Ethical and Policy Implications of Limiting Growth in Children with Severe Disabilities”** (Moderator) University of Washington. Seattle. WA
- May 2007 **“Disclosing Incidental Findings in Pediatrics”** Managing Incidental Findings in Human Subjects Research: From Imaging to Genomics, University of Minnesota., Minneapolis, MN
- Oct 2005 **“Bioethics, excellence, and physicians-in-training”** AMSA Bioethics Conference. University of Arizona. Tucson AZ
- July 2005 **“Ethical issues in marketing genetic tests”** Linda Fox Memorial Address. 10th Annual Genetics and Ethics in the 21st Century. The Given Institute of the University of Colorado. Aspen, CO
- Feb 2004 **“Bioethics in medical practice”** American Medical Student Association Regional Bioethics Conference, Johns Hopkins School of Medicine. Baltimore, MD
- April 2003 **“Prenatal and newborn genetic testing”**Cystic Fibrosis: Ethical issues in Diagnosis and Treatment. The Childrens’ Hospital. Denver, CO

- April 2003 **“Ethical issues with genetic testing for cystic fibrosis”** Conference on Genetics, Deafness and Disability, Galludet Universit. Washington, DC
- 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
- June 2002 **“Ethical Issue in cystic fibrosis newborn screening: From data to public health policy”** Mid Atlantic CF Retreat. Villanova, PA
- 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
- 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
- March 2000 **“Informed consent for in utero gene transfer research”**
Genetics Short Course, University of Michigan, Ann Arbor, MD
- INVITED WORKSHOP PRESENTATIONS (selected, since 2002)
- July 2005 **“Disclosing individual research results to participants: A results-focused approach to study design”** Reporting Results of Genetic Research Workshop. Center for Integration of Research on Genetics and Ethics. Stanford University. Palo Alto CA
- May 2005 **“Worlds in Collision: ethical and policy implications of carrier screening/prenatal diagnosis and newborn screening for the same condition”** Hastings Center. Garrison, NY
- March 2005 **“Interpreting the definitions of risk in the federal research regulations”** Cystic Fibrosis Foundation Data Monitoring Committee Annual Meeting. Dallas, TX
- August 2004 **“Balancing benefits and risks in CF newborn screening”** CF Newborn Screening Implementation Conference, Cystic Fibrosis Foundation, Bethesda, MD
- Feb 2005 **“Ethical issues in newborn screening research”** Fragile X Study Group, University of North Carolina. Chapel Hill, NC
- Dec 2004 **“Cystic fibrosis newborn screening: policy issues”** Maryland Advisory Council on Hereditary and Congenital Disorders, Baltimore, MD
- April 2003 **“Ethical Issues with Cystic fibrosis Newborn Screening”** Hastings Center. Garrison, NY

- July 2002 **“Consent Monitoring”** Cystic Fibrosis Foundation Data Safety and Monitoring Committee Annual Meeting. Denver, CO
- GRAND ROUNDS (since 2000)
- April 2008 **“Show Me the Money: Responding to parental requests for medical interventions in children with profound disabilities.”** David Green Memorial Lecture. Department of Pediatrics Grand Rounds. University of Utah. Salt Lake City, Utah.
- March 2008 **“Show Me the Money: Responding to parental requests for medical interventions in children with profound disabilities”** Pediatric Grand Rounds University of California-Davis. Davis, CA
- May 2005 **“Ethical issues in Pediatric Research”** 17th Annual Stuart Stevenson Lecture. UMDNJ- New Jersey Medical School, Newark, NJ
- April 2004 **“Ethics and excellence: getting to the top of the hill”**, AOA Induction Keynote Address, New Jersey Medical School, Newark, NJ
- March 2004 **“Direct to consumer advertising for genetic tests”**
Pediatric Grand Rounds, University of Wisconsin Department of Pediatrics. Madison, WI
- April 2003 **“Gene therapy and research in children”** Pediatric Grand Rounds, University of Colorado. Denver, CO
- March 2003 **“The Commercialization of Genetics”** Inaugural RJ Fellowship Symposium, Muhlenberg College. Allentown, PA
- Feb 2002 **“Cystic fibrosis newborn screening”** Department of Pediatrics Grand Rounds. Columbia University. New York, NY
- June 2000 **“Bioethics: a new medical specialty”** Anesthesia Grand Rounds, Boston Children’s Hospital. Boston, MA