

Benjamin Simon Wilfond MD

June 2019

CONTACT INFORMATION

Treuman Katz Center for Pediatric Bioethics, 1900 Ninth Avenue, M/S: JMB-6, Rm 683, Seattle, WA 98101; 206-884-8355, bwilfond@u.washington.edu

PERSONAL DATA

Place of Birth: Washington DC
Date of Birth: November 19, 1959

EDUCATION

1977-1981 BS with Honors in Philosophy and Biology
Muhlenberg College
Allentown, PA

1981-1985 MD
New Jersey Medical School
Rutgers University
(formerly College/University of Medicine and Dentistry of New Jersey)
Newark, NJ

POST-GRADUATE TRAINING

1985-1988 Residency
Department of Pediatrics
University of Wisconsin Hospital and Clinics
Madison, WI

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

FACULTY POSITIONS HELD

University of Wisconsin

1991-1992 **Instructor**
Department of Pediatrics
School of Medicine and Public Health

University of Arizona

1992-1998 **Assistant Professor**
Department of Pediatrics
College of Medicine

1998 **Associate Professor** (with tenure)
Department of Pediatrics
College of Medicine

NIH Clinical Center

1998-2006

Head

Section on Ethics and Genetics
Department of Bioethics

National Human Genome Research Institute

1998-2000

Co-Director

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

2000-2003

Head

Bioethics Research Section
Medical Genetics Branch

2003-2006

Head

Bioethics and Social Policy Unit
Behavioral and Social Research Branch

Johns Hopkins University

1998-2006

Visiting Associate Professor

Department of Pediatrics
School of Medicine

2003-2006

Adjunct Associate Professor

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

University of Washington

2006-2018

Professor and Chief

Division of Bioethics
Department of Pediatrics
School of Medicine

2018-present

Professor and Chief

Division of Bioethics and Palliative Care
Department of Pediatrics
School of Medicine

2006-present

Professor

Division of Pulmonary and Sleep Medicine
Department of Pediatrics
School of Medicine

2006-present

Adjunct Professor

Department of Bioethics and Humanities
School of Medicine

2008-present

Faculty

Institute for Public Health Genetics
School of Public Health

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

HONORS AND AWARDS

1979 Alpha Psi Omega (theatre)
Muhlenberg College
1980 Omnicron Delta Kappa (leadership)
Muhlenberg College
1996 Faculty Fellowship
Udall Center for Studies in Public Policy, University of Arizona
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
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
2003 Distinguished Alumni Award
New Jersey Medical School
2004 Alpha Omega Alpha
New Jersey Medical School
2006 Distinguished Alumni Award
University of Medicine and Dentistry of New Jersey
2006 American Pediatric Society
2010 Fellow
Hastings Center
2017 Alumni Achievement Award in Medicine-Bioethics
Muhlenberg College

BOARD CERTIFICATION

1992 - present Sub-Board of Pediatric Pulmonology #371
(MOC Cycle 12/14/2013 - 12/20/2018)
1989 - present American Board of Pediatrics #417
(MOC Cycle 12/14/2013 - 12/20/2018)

CURRENT LICENCES TO PRACTICE

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

TEACHING RESPONSIBILITIES

(a) Undergraduates, Medical Students, Law Students, Pharmacy Students

1. Table of University of Arizona School of Medicine Courses Taught

Course	Title	Credits	Year(s)	Students	Responsibility
MED 505	Social and Behavioral Sciences	10 hour module	1994-1998	120	Module Coordinator
Gen 512	Medical Ethics	1	1995-1998	10-15	Course Director

2. Table of UW School of Medicine Courses Taught

Course	Title	Credits	Year(s)	Students	Responsibility
HUBIO 548	Cases in Clinical Ethics	1	2009 2012 2013 2014	200	Lectures on ethical issues in pediatrics and ethical issues in clinical research
PEDS 665	Clinical Clerkship	Up to 24	2008-present	5-10	1-2 lecture each year
MEDSC525	Ecology of Health & Medicine		2018		Discussion group leader on cases related to diversity

3. Table of UW Law School Courses Taught

Course	Title	Credits	Year(s)	Students	Responsibility
H510	Topics in Law and Medicine	1-4	2011	15-20	Lecture on growth attenuation in children
H504	Legal, Ethical & Social Issues In Public Health Genetics	3	2011	15-20	Lecture on genetic testing in children

4. Table of UW Arts and Sciences Courses Taught

Course	Title	Credits	Year(s)	Students	Responsibility
BH 311	Ethical Issues in Modern Medicine	3	2009, 2010 2011, 2012 2013, 2014 2015, 2016 2017, 2018	100	Lecture on enhancements in children
BH 201	Topics in Bioethics & Humanities	2	2016, 2017 2018	60	Lecture on ethics in clinical trials

5. Table of UW Pharmacy Courses Taught

Course	Title	Credits	Year(s)	Students	Responsibility
PHRMRA 554	Advanced Medical Products Regulation	2	2010	70	Lecture on ethics in clinical trials
PHRMRA 524	Introduction to Clinical Trials	3	2016	70	Lecture on ethics in clinical trials

(b) Subspecialty fellows

UNIVERSITY OF ARIZONA

1992-1998

Supervise Pediatric Pulmonary Fellows (Inpatient and Outpatient)

JOHNS HOPKINS UNIVERSITY

1998-2006

Supervise Pediatric Pulmonary Fellows (Outpatient Clinic)

NIH CLINICAL CENTER

1998-2006

Supervise Bioethics Fellows (Bioethics Consult Service)

SEATTLE CHILDRENS HOSPITAL

2006-present

Supervise Bioethics Fellows (Bioethics Consult Service)

Supervise Pediatric Pulmonary Fellows (Outpatient Clinic)

(c) Trainees

Dissertation Committees

1997

Greg Loeben (PhD)

“Medical Futility and the Goals of Medicine”

Department of Philosophy

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

2001

Lois Loescher (PhD)

“Perceived Risk of inherited susceptibility to cancer”

College of Nursing

University of Arizona

2003

Elizabeth Lardy (MSc)

“Genetic Counselors’ Descriptions of Down Syndrome”

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

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

- 2006 Meredith Weaver (MSc)
 “Genetic counselors engaging in advocacy”
 Department of Health Behavior and Society
 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
- 2005 Ingrid Burger (PhD)
 “Radiologist attitudes about whole body CT Scanning”
 Program in Law, Society and Ethics
 Johns Hopkins School of Public Health
- 2007 Rachel Jacobson (MSc)
 “Moral Value Conflicts Among Genetic Counselors”
 Department of Health Behavior and Society
 Johns Hopkins School of Public Health
- 2008 Aaron Goldenberg (PhD)
 “Newborn screening and public policy”
 Department of Bioethics
 Case-Western Reserve University
- 2010 Alison Archibald (PhD)
 “Exploration of view about population genetic carrier screening for fragile X syndrome”
 Laboratory and Community Genetics
 University of Melbourne
- 2011 Marilyn Hair (MPH)
 “Take Up Your Bed and Walk: A Case Study of Adolescent Health Transition in a Cystic Fibrosis Care Center”
 Institute for Public Health Genetics
 University of Washington School of Public Health
- 2011 Mitzi Murray (MA)
 “Returning research results in children with monogenetic diabetes”
 Department of Bioethics and Humanities
 University of Washington School of Medicine
- 2012 Jen Guon JD (MA)
 “Continuing Pregnancy After a Prenatal Trisomy 13-18 Diagnosis: An Examination of Care, Disability, and Parental Perspectives “
 Department of Bioethics and Humanities
 University of Washington School of Medicine
- 2014 Tracy Brazg (MA)
 “Clinical ethics consultation and advocacy”
 Department of Bioethics and Humanities

	University of Washington School of Medicine
2015	Holly Peay (PhD) "Community-engaged approaches to explore research priorities in Duchenne an Becker muscular dystrophy" Leiden University
2017	Kristi Klee(MA) "Ethics consults for disagreements about tracheostomies" Department of Bioethics and Humanities University of Washington School of Medicine
2017	Leah Kroon (MA) "Ethical implications of using puberty blocking medications in adolescents with gender identity issues" Department of Bioethics and Humanities University of Washington School of Medicine
2014- 2016	Tracy Brazg (PhD) "Inter-professional education in ethics" University of Washington School of Social Work

B.POST DOCTORAL RESEARCH TRAINEES

1999-2001	Carol Freund PhD
2003-2005	Vardit Ravitsky PhD
2006-2009	Doug Opel MD
2009-2010	Stephanya Shear MD
2009-2011	Mitzi Murray MD
2010-2012	Jenn Guon JD
2015-2017	Anita Shah MD

(d)Teaching Committees

UNIVERSITY OF ARIZONA

1996-1998	Admissions Committee Genetic Counseling Graduate Program
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JOHNS HOPKINS UNIVERSITY

2001-2006	Executive Committee Genetics Counseling Graduate Program National Human Genome Research Institute /Johns Hopkins University
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UNIVERSITY OF WASHINGTON

2007-2008	Masters Program Evaluation Committees Department of Bioethics and Humanities
2013	Ethics and Professionalism Working Group Curriculum Renewal Committee

2009-present
Admission Committee
MA Program
Department of Bioethics and Humanities

EDITORIAL RESPONSIBILITIES

1995-1999
Editorial Board
American Journal of Medical Genetics

2002-2009
Editorial Board
American Journal of Bioethics

2013-Present
Editorial Board
Journal of Genetic Counseling

2013-Present
Section Co-editor, Challenging Cases in Research Ethics
American Journal of Bioethics

2017-Present
Editorial Committee
Hastings Center Report

SPECIAL GOVERNMENT RESPONSIBILITIES

Canadian Institutes for Health Research

2017-present
Standing Committee on Ethics

National Institutes of Health

1991
Study Section Member
Cystic Fibrosis Studies
National Human Genome Research Institute

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

1994
Study Section Member
Studies of Genetic Testing and Counseling for Heritable Cancer Risks
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

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

1998-1999
Working Group on Cystic Fibrosis Educational Materials
National Human Genome Research Institute

2001-2004
Ethics Working Group (Co-Chair)
National Children's Study

	National Institute of Child Health and Development
2001-2012	Data and Safety Monitoring Board Childhood Asthma Research and Education Network (CARE) National Heart Lung and Blood Institute
2002	Study Section Member (Ad Hoc for ELSI proposals) National Heart Lung and Blood Institute
2002-2004	Working Group on Bioethics Literature National Library of Medicine
2005-2006	Medical Sequencing Working Group (ELSI Committee) National Human Genome Research Institute
2007	Ethical Issues in Human Subjects Research Special Emphasis Panel Center for Scientific Review
2007-2012	Data and Safety Monitoring Board Childhood Adenoidectomy Tonsillectomy Study (CHAT) National Heart Lung and Blood Institute
2008-2012	National Children’s Study Advisory Committee National Institute of Child Health and Development
2008-2013	*Biobank Working Group Advisory Committee (2010-2013) *Operations Group (2009- 2013) *Consultation Working Group(2008-2013) (Chair 2009-2013) Clinical Research Ethics Key Function Committee Clinical and Translational Science Award Consortium National Center for Advancing Translational Science
2008-2013	Pediatric Research Ethics Working Group Clinical and Translational Science Award Consortium National Center for Advancing Translational Science
2008-2013	Scientific Advisory Committee Human Genetic Cell Repository National Institute for General Medical Sciences
2011	Special Emphasis Panel: RFA-HG-11-022, “The Electronic Medical Records and Genomics (eMERGE) Network, Phase II – Pediatric Study Investigators.” National Human Genome Research Institute
2012	Special Emphasis Panel: Centers of Excellence for ELSI Research National Human Genome Research Institute
2014	Societal and Ethical Issues in Research Study Section (ad hoc) Center for Scientific Review
2013-2017	*Steering Committee *Pediatrics Working Group (Chair 2014-2017) *Return of Results Working Group

*Informed Consent and Governance Working Group
 Clinical Sequencing Exploratory Research Consortium
 National Human Genome Research Institute

2013- present Data and Safety Monitoring Committee
 Pediatric pulmonary interventions in muscle weakness
 National Heart Lung and Blood Institute

2014-present Clinical Research Ethics Consultation Collaborative (Chair)
 (Ad hoc consortium of research ethics consultants at CTSA)

2015- present Ethics/Regulatory Core, Health Care Systems Research Collaboratory

2016- present Societal and Ethical Issues in Research (SEIR) Study Section
 Center for Scientific Review

2016- present Data and Safety Monitoring Committee
 Pediatric Adeono-toniselectomy Study (PATS)
 National Heart Lung and Blood Institute

Food and Drug Administration

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

1999-2006 Pediatric Ethics Working Group

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

2008-present Pediatric Ethics Subcommittee, Pediatric Advisory Committee

Center for Disease Control and Prevention

2003 Cystic Fibrosis Newborn Screening Planning Committee

2004 Cystic Fibrosis Newborn Screening Writing 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

SPECIAL PROFESSIONAL ORGANIZATIONAL RESPONSIBILITIES

American Academy of Pediatrics

1996-2000 Committee on Bioethics

1997-1999 Working Group on Umbilical Cord Blood Banking (Co-Chair)

1999-2000 Newborn Screening Taskforce

Association of Bioethics Program Directors

2010-2012 Vice President/President Elect

2012-2014 President

2014-2016 Past President

2016-present Chair, Scholarship and Funding Taskforce

American Association of Bioethics and Humanities

1989-1990 Program Committee

Student Interest Group (Society for Health and Human Values)

2000 Annual Meeting Program Committee

American College of Medical Genetics

2009-2018 Bioethics and Legal Issues Working Group

Newborn Screening Translational Research Network

American Medical Student Association

1983-1984 Board of Trustees

1984-1985 Standing Committee on Bioethics
(Founder and National Coordinator)

American Society of Human Genetics

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

1992-1995 Social Issues Committee

2014- 2015 Pediatric Genetic Testing Working Group

American Thoracic Society

1993-2005 Bioethics Task Force

1998-2001 Genetics, psychosocial, economics, and ethical issues writing group.
Taskforce on Standards of Diagnosis and Management of Individuals
with Alpha-1 Antitrypsin Deficiency

2003-2004 Research Opportunities and Challenges in Pediatric Respiratory
Medicine Writing Group

Cystic Fibrosis Foundation

2003-2006 Gene Modifier Scientific Advisory Committee

2004 Planning Committee

Implementation of CF Newborn Screening Workshop

2000-present Data Safety and Monitoring Committee

(Chair, Sildenafil, Simvastatin, Baby Observations studies)

Northwest Association for Biomedical Research

2009-present Board of Trustees
2010-2014 Co-Chair, Program Committee, Board of Trustees

Pediatric Academic Societies Meeting

2013 Abstract Reviewer for Clinical Bioethics

Other

2003-2005 Bioethics Advisory Board
Wyeth Pharmaceuticals
2003-2006 RJ Fellowship Advisory Board
Muhlenberg College
2007-2017 Bioethics Advisory Committee
March of Dimes
2007-Present Newborn Screening Advisory Committee
Washington State Health Department

SPECIAL ADVISORY RESPONSIBILITIES

2012-2016 Advisory Committee
Parental Expectations, Holly Peay/Parent Project Muscular Dystrophy
2012- 2017 Return of Results Committee
NEXTMED, G Jarvik/U Washington
2013- 2017 Advisory Committee
NEXUS, Don Bailey/Research Triangle Institute
2012-2016 Working Group
Disclosing Genomic Incidental Findings in a Cancer Biobank,
Susan Wolf, University of Minnesota

SPECIAL LOCAL RESPONSIBILITIES**University of 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

University of Arizona

1992-1998 Ethics Committee
University Medical Center
1993-1998 Human Subjects Committee

	University of Arizona
1993-1998	Director Infant Apnea/Bronchopulmonary Dysplasia Program University Medical Center
1995-1997	Associate Director Cystic Fibrosis Center University Medical Center
1997-1998	Co-Director Cystic Fibrosis Center University Medical Center
1997-1998	Ethics Committee Tucson Medical Center
1998	Ethics Committee (Chair) University Medical Center

National Institutes of Health

1998-2005	Institutional Review Board (Associate chair) National Human Genome Research Institute
1998-2006	Bioethics Consultation Service NIH Clinical Center
1998 -2006	Ethics Committee NIH Clinical Center
1999- 2000	Institutional Review Board National Heart Lung and Blood Institute
2000-2002	Institutional Review Board National Institute of Child Health and Development
2000-2006	Committee on Scientific Conduct and Ethics Division of Intramural Research
2003-2006	Deputy Director Bioethics Core Office of the Clinical Director National Human Genome Research Institute
2005-2006	Human Subjects Research Advisory Committee Division of Intramural Research
2005-2006	Institutional Review Board (chair) National Human Genome Research Institute

Seattle Children's

2006- 2016	Chief Bioethics Consult Service
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2007-2017	Board of Trustees Quality Committee
2007-2008	Diversity Center Director Search Committee
2009-2011	ID Center Search Committees (Chair)
2013	Diversity and HealthCare Equality Director Search Committee
2006-present	Director Treuman Katz Center for Pediatric Bioethics
2006-present	Ethics Committee
2007-present	Steering Committee Center for Clinical and Translational Research
2007-present	Center Director Advisory Committee Seattle Children's Research Institute

Department of Bioethics and Humanities, University of Washington

2008-2009	Junior Faculty Search Committee (chair)
2012 -2013	Senior Faculty Search Committee (chair)
2009-present	Masters Program Admission Committee

University of Washington School of Medicine

2013	Ethics and Professionalism Working Group Curriculum Renewal Committee
2013-2015	Bioethics and Humanities Chair Search Committee

Institute for Translational Health Sciences

2007-2013	Regulatory Support and Bioethics Core (co director)
2009-2013	ITHS Steering Committee (chair)
2007-present	Research Bioethics Consult Service (director)
2012-present	ITHS Data and Safety Monitor Committee Chair (2014 –present) <i>Phase III Triiodothyronine Supplementation for Infants After Cardiopulmonary Bypass</i> Chair (2012-2015) - <i>Pediatric Leukemia Adoptive Therapy (PLAT)-01: A Phase I Feasibility and Safety Study of Cellular Immunotherapy for Relapsed Pediatric CD19+ Acute Lymphoblastic Leukemia Using Autologous T-cells Lentivirally Transduced To Express a CD19-Specific Chimeric Antigen Receptor</i> Chair (2013) <i>Prospective, Randomized, Multiple Site Clinical Trial Comparing the Effectiveness of Novel Pressure Based Insoles to Current Care For Ulcer Prevention</i>

2016- present Faculty Lead
Regulatory Knowledge and Support Module

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

2007-2011 Internal Advisory Committee

2010- 2011 Chair, Internal Advisory Committee

RESEARCH FUNDING

Active

The Dog Aging Project: Genetic and Environmental Determinants of Healthy Aging in Companion Dogs
U19AG057377 NIH/NIA Promislow PI

9/1/18 – 8/31/23

Role: Co-Investigator (5%) \$11,688

Measuring Perceptions of Utility of Clinical Genome Sequencing: Instrument Development and Validation

U01HG006485 NIH/NHGRI

McGuire PI

9/2018-5/2019

Role: Co- Investigator (3%) \$17,112

“What it means for our family” – Video Decision Supports for Parents Considering Chronic Pediatric Mechanical Ventilation

National Palliative Care Research Center

Boss (PI)

07/2018-06/2020

Role: Co- Investigator (3%)

“Exome Sequencing in Diverse Populations in Colorado and Oregon”

UO1 HG007292 NIH / NHGRI

Goddard /Wilfond MPI

8/1/17 - 5/31/21

Role: Multiple PI with K. Goddard; Subcontract PI (20%) \$2,674,259

“Institute of Translational Health Sciences”

UL1 TR000423- NIH/NCATS

Disis PI

6/1/17-5/31/22

Faculty Lead, Regulatory Support and Knowledge Module and Director, Bioethics Consult Service (10%)
\$10,899,655

Past

“Assessing the impact of videos and comics on knowledge and attitudes about randomization for research on medical practices”

Greenwall Foundation: Making a Difference in Real-World Bioethics Dilemmas Cho/Wilfond MPI

2/2015 to 2/2016

Co-Principal Investigator (5%) \$202,000

“Beyond Consent: Patient Preferences for Governance of the Use of Clinical Data and Samples”

R01 LM012180 NIH/NLM Lee (PI)
09/2014-12/2017
Role: Co-Investigator (5%)

“Nurse-Bioethics Liaison Program”
Seattle Children’s Hospital Guild Association
Guild Focus Program Wifond PI
10/2014- 9/2017
Principal Investigator (8%) \$500,000

“Attitudes about the Ethics of Research on Medical Practices”
UL1 TR000423-07S1 NIH/NCATS Wifond/Magnus Co-Project Directors/Disis PI
9/2013 to 5/2015
Co-Project Director (10%) \$475,0000

“Clinical Implementation of Carrier Testing using Next Generation Sequencing”
UM1 HG007292 NIH/NHGRI Goddard/Wifond MPI
06/2013-12/2017
Role: Multi-Principal Investigator (20%)

“Research Ethics Consultation: State of the Art”
VHA National Center for Ethics in Health Care Health IPA Wifond PI
1/2012 – 3/2012
Principal investigator (5%) \$19,172

“Disclosing Genomic Incidental Findings in a Cancer Biobank: An ELSI Experiment”.
R01 CA154517 Peterson/Wolf/Koenig MPI
09/2011-07/2016
Role: Consultant

“Bioethics Consultation Standardization and Data-Sharing”
UL1 RR025014-04S1 NIH/NCRR Wifond Project Director/Disis PI
9/2010-5/2011
Project Director (15%) \$428,712

“Center for Genomics and Health Care Equality”
P50 HG 003374 NIH/ NHGRI Burke PI
4/2010-3/2015
Co-Investigator (5%) \$45,246 (subcontract)

“Ethical Approaches to Genotype-Driven Research Recruitment”
RC1-HG005787 NHGRI Beskow PI
9/2009 – 9/2011
Co-investigator (12%) \$120,201

“Parental Permission and the Adolescent Assent Process”
HHSN2692009001309 NIH Clinical Center Department of Bioethics Wifond PI

3/2009-12/2010

Principal investigator (3%) \$29,000

“The Ethical and Policy Implications of Growth Attenuation in Children with Profound Developmental Disabilities”

Greenwall Foundation-Bioethics Award Program

Wilfond/ Miller MPI

1/2008 to 12/2008

Principal Investigator (2.5%) \$40,000

“*Institute of Translational Health Sciences*”

UL1 RR 025014-01 NIH/NCRR

Disis PI

9/17/2007-5/31/2012

Co-Director, Regulatory Support and Bioethics Core (20%) \$6,513,229

“The Ethical and Policy Implications of Growth Attenuation in Children with Profound Developmental Disabilities”

Walter Chapman Simpson Center for the Humanities B Wilfond PI

1/2008 to 12/2008

Principal Investigator \$17,000

“Monogenic Diabetes in the SEARCH study”

Juvenile Diabetes Research Foundation Research Grant Program

Pihoker PI

11/07 to 11/2008

Investigator (2.5%) \$513,394

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

The Doris Duke Charitable Foundation

Feinberg PI

10/2005 to 9/2010

Key Investigator (5%) \$2,083,335

“Social Construction of Benefit in Gene Transfer Research”

R01 HG 002087 National Human Genome Research Institute

Henderson PI

9/1999-12/2006

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

“Genetic Screening in Primary Care: Ethics and Policy”

R29 HS08570 Agency for Health Care Policy and Research

Wilfond PI

9/1994- 9/1998

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"

National Center for Human Genome Research

Wilfond PI

6/1990 -12/1990

Principal Investigator \$6,000 (contract)

"Clinical Fellowship Award"

Cystic Fibrosis Foundation

Wilfond PI

1989-1990

Principal Investigator \$31,000

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

Squibb Co

Sachs/Wilfond PI

1985

Writer and Executive Producer (video production) \$8,500

PUBLICATIONS

A REFEREED 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
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27. **Wilfond BS**. Breaking the Sounds of Silence: Respecting People With Disabilities and Reproductive Decision Making. *Am J Bioeth*. 2017 Jan;17(1):37-39.
28. Kraft SA, Porter KM, Shah SK, **Wilfond BS**. Comprehension and Choice Under the Revised Common Rule: Improving Informed Consent by Offering Reasons Why Some Enroll in Research and Others Do Not. *Am J Bioeth*. 2017 Jul;17(7):53-55.
29. **Wilfond BS**, Kraft SA. Attending to the Interrelatedness of the Functions of Consent. *Am J Bioeth*. 2017 Dec;17(12):12-13
30. Porter KM, Danis M, Taylor HA, Cho MK, **Wilfond BS**. Defining the Scope and Improving the Quality of Clinical Research Ethics Consultation: Response to Open Peer Commentaries About the National Collaborative. *Am J Bioeth*. 2018 Feb;18(2):W13-W15

31. **Wilfond** BS, Porter KM, Creevy KE, Kaeberlein M, Promislow D. Research to Promote Longevity and Health Span in Companion Dogs: A Pediatric Perspective. *Am J Bioeth.* 2018 Oct;18(10):64-65.
32. Wilfond BS, Porter KM. Justifying Investigator/Clinician Consent When The Physician-Patient Relationship Can Support Better Research Decision-Making, *Am J Bioeth.* 2019, 19:4, 26-28
33. Kraft SA, Garrison NA, Wilfond BS. Understanding as an Ethical Aspiration in an Era of Digital Technology-Based Communication: An Analysis of Informed Consent Functions. *Am J Bioeth.* 2019;19(5):34-36.

F. CHALLENGING CASES IN RESEARCH ETHICS (Co-Editor with Holly Taylor and Liza Johnson)

1. Managing disclosure of research misconduct by a graduate student to a university mental health professional during a clinical counseling session. *Am J Bioeth.* 2013 Oct; 13(10):68.
2. The ethics of contacting family members of a subject in a genetic research study to return results for an autosomal dominant syndrome. *Am J Bioeth.* 2013 Oct; 13(10):61.
3. The ethics of disclosing to research subjects the availability of off-label marketed drugs. *Am J Bioeth.* 2014 Apr;14(4):51.
4. Ethics of continuing to provide a drug on an open-label extension study for an "unapproved indication". *Am J Bioeth.* 2014 Apr;14(4):56
5. Ethical implications of social media in health care research. *Am J Bioeth.* 2014 Oct;14(10):58-9.
6. The obligations to report statutory sexual abuse disclosed in a research study. *Am J Bioeth.* 2014 Oct;14(10):50.
7. Navigating parental permission for neonatal research. *Am J Bioeth.* 2015 Apr ;15(4):76.
8. Protecting research subject welfare in preventive trials for autosomal dominant Alzheimer's disease. *Am J Bioeth.* 2015 Apr;15(4):83-4
9. Is it ethical to enroll cognitively impaired adults in research that is more than minimal risk with no prospect of benefit? *Am J Bioeth.* 2015 Oct;15(10):64-5.
10. Recontact and recruitment of young adults previously enrolled in neonatal herpes simplex virus research. *Am J Bioeth.* 2015 Oct;15(10):56-7.
11. Obligations to Act on Patient Reported Outcomes in Electronic Health Records. *Am J Bioeth* , 2016 April; 16(4), p. 62
12. Selecting Children for an Autism Spectrum Disorder Study: Justice and Geography. *Am J Bioeth*, 2016 April; 16(4), pp. 69–70
13. Studying the role of financial incentives to promote hepatitis B vaccination in a community clinic. *Am J Bioeth* 2016 Oct; 16(10): 75-76.
14. When a clinical trial is the only option. *Am J Bioeth.* 2016 Oct; 16(10): 67-68
15. Should Patients Be Required to Undergo Standard Chemotherapy Before Being Eligible for Novel Phase I Immunotherapy Clinical Trials? *Am J Bioeth.* 2017 Apr;17(4):66-67.

16. Genotype-Driven Recruitment in Population-Based Biomedical Research. *Am J Bioeth.* 2017 Apr;17(4):58-59
17. Expanded Access for Nusinersen in Patients With Spinal Muscular Atrophy: Negotiating Limited Data, Limited Alternative Treatments, and Limited Hospital Resources. *Am J Bioeth.* 2017 Oct;17(10):66-67.
18. A Trial to Test a Novel Approach to Diabetes Prevention. *Am J Bioeth.* 2017 Oct;17(10):74-75.
19. Is It Ethically Appropriate to Refuse to Compensate Participants Who Are Believed to Have Intentionally Concealed Medical Conditions? *Am J Bioeth.* 2018 Apr;18(4):83-84.
20. Involving Pregnant Women in Research: What Should We Recommend When the Regulations Seem Ethically Problematic? *Am J Bioeth.* 2018 Apr;18(4):91-92.
21. A Randomized Trial of Rapamycin to Increase Longevity and Healthspan in Companion Animals: Navigating the Boundary Between Protections for Animal Research and Human Subjects Research. *Am J Bioeth.* 2018 Oct;18(10):58-59
22. Ethical Considerations for Unblinding a Participant's Assignment to Interpret a Resolved Adverse Event. *Am J Bioeth.* 2018 Oct;18(10):66-67
23. Should Research Participants Be Notified About Results of Currently Unknown but Potential Significance? *Am J Bioeth.* 2019;19(4):73-7
24. The Limitations of "Boilerplate" Language in Informed Consent: Single IRB Review of Multisite Genetic Research in Military Personnel. *Am J Bioeth.* 2019;19(4):81-82

E. 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
2. Ashwal G, Magnus D, Thomas A, and Wilfond B. "Research on Medical Practices" Institute of Translational Health Sciences and Seattle Children's Hospital 2015

SELECTED PRESENTATIONS

FEDERAL TESTIMONY

- May 1997 **"Informed consent and participation of children in research"**
Subcommittee on human resources, Committee on Government Reform and oversight,
House of Representatives
- Aug 2013 **"Quality Improvement Ethics"**
Hearings on Standard of Care Research, Department of Health and Human Services

INTERNATIONAL PRESENTATIONS (SINCE 2000)

- July 2000 **"Informed consent for in utero gene transfer research"** 3rd Brazilian Congress on
Bioethics. Porto Alegre, Brazil
- July 2001 **"Emerging ethical issues in pharmacogenomics"** Universidad Nova de Lisboa, Portugal
- June 2002 **"Genetics Research"** Ethical and Regulatory Aspects of Human Subjects Research, Seoul,
Korea

- 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
- 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
- Nov 2006 **“Ethical issues in pediatric research”, “Ethical issues in genetics research”** NIH Fogarty Center Latin American Seminar on Research Ethics, Buenos Aries, Argentina
- Sept 2016 **“Technological Interventions in Children with Profound Disabilities: Navigating Family & Professional Values”**
“Disclosing Incidental Findings from Genomic Testing- the ‘Benefit to Family Rationale”
8th National Pediatric Bioethics Conference, The Royal Children’s Hospital, Melbourne, Australia

FEDERALLY SPONSORED COFERENCES (since 2003)

- March 2003 **“The National Children’s Study: ethical issues in longitudinal research”** Committee on Clinical Research Involving Children IOM. Irvine, CA
- June 2003 **“Ethical Issues in Pediatric Longitudinal Research: Looking Back, thinking forward”** (Co chair) National Children’s Study Workshop, NICHD. Bethesda, MD
- Nov 2003 **“Overview of Cystic Fibrosis Newborn Screening Approaches”**
Newborn Screening for Cystic Fibrosis Workshop, CDC. Atlanta, GA
- 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
- July 2004 **“Ethical Issues in Disclosing Genetics Research Results”**
NHLBI Working Group on Research Results. Bethesda MD
- Jan 2006 **“The Participation of Children in Genetics Research”**
National Children’s Study Federal Advisory Committee Meeting
Gaithersburg, 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
- Nov 2008 **“Prenatal testing for CMV: Lesson from cystic fibrosis”** Congenital Cytomegalovirus Conference. Center for Disease Control and Prevention. Atlanta GA
- 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
- May 2010 **“Putting multiplex in perspective: a view from the outside”**. The multiplex Initiative: Implications for Personalized Medicine. NHGRI Detroit, MI

- July 2010 **“Research Bioethics Consultation: More potential than sequencing genomes”**. Secretary’s Advisory Committee on Human Research Protection. Washington, DC
- Nov 2010 **“Bioethics Consultation and Data-sharing”**. Clinical Research Ethics Key Function Committee Annual Meeting. NCRR Chicago, IL (conference moderator)
- Nov 2010 **“Ethical issues about genetic testing for children at risk for cancer”** Li-Fraumini Syndrome Workshop NCI, Bethesda MD
- Feb 2012 **“What are the psychosocial and ethical implications associated with sapropterin response or non-response?”** Phenylketonuria Scientific Review Conference: State of the Science and Future Research Needs. NICHD. Bethesda, MD
- Oct 2013 **“Ethical Implications of Comparative Effectiveness Research”** (Workshop Moderator) Clinical Research Ethics Key Function Committee Annual Meeting, NCATS, Atlanta GA
- Oct 2013 **“Developing a Taxonomy for Preconception Carrier Testing”** Clinical Sequencing Exploratory Research Annual Meeting. NHGRI. Bethesda, MD
- Feb 2014 **“Attitudes about Research on Medical Practices”** NIH Collaboratory National Meeting, Bethesda, MD
- Oct 2014 **“Pediatric Genomics: Conflicts and disclosure”** (moderator) Clinical Sequencing Exploratory Research Annual Meeting. NHGRI. Bethesda, MD
- Dec 2014 **“Public Attitudes about research on medical practices”** NIH Collaboratory Grand Rounds Webinar.
- Dec 2014 **“Empirical data on public attitudes about research on medical practices”** Ethical Review and Oversight Issues in Research Involving Standard of Care Interventions: A Workshop. Institute of Medicine. Washington DC.
- March 2015 **“Lessons from Pediatric Gene Transfer Research: Implications for Novel Mitochondrial techniques”** Workshop of the Committee on Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases. Institute of Medicine. Washington, DC.
- April 2016 **“A genome-scale carrier screening study: Lessons learned for implementation research and clinical service”** Clinical Sequencing Exploratory Research Consortium Meeting. Seattle, WA
- April 2016 **“Comparison of IRB and Patient views for ROMP”** NIH Health Care Systems Research Collaboratory Ethics Supplements Summit Meeting, Baltimore, MD
- Sept 2015 **“Patient-Centered Research: From Consent to Outcomes”** Integrating Genome Sequencing into Clinical Care: CSER and Beyond (NHGRI) Bethesda, MD
- October 2016 **Willingness to participate in research on medical practices and the implications of the “investigational misconception for informed consent”** NIH Collaboratory Grand Rounds. Webinar

Wilfond B, Kauffman TL, Jarvik GP, Reiss JA, Richards CS, McMullen C, Gilmore M, Himes P, Kraft SA, Porter KM, Schneider J, Punj S, Leo MC, Dickerson JF, Lynch F, Clarke E, Rope AF, Lutz K, **Goddard KAB**. “Lessons learned from a study of genomics -based carrier screening for reproductive decision-making.” Health Affairs briefing on precision medicine special issue, Washington, DC, May 8, 2018.

NATIONAL PROFESSIONAL MEETINGS (since 2005)

- March 2005 **“Bioethics: From the Margin to the Mainstream”** American Medical Student Association National Convention. Arlington, VA
- 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
- 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 2007 **“Ashley Revisited: Is Growth Attenuation Ever Justified in a Profoundly Disabled Child?”** (Moderator) “American Society of Bioethics and Humanities Annual Meeting Washington, DC;
- Oct 2007 **“Family perspectives on returning research results”** (moderator) ASCO/COG Symposium on ethical considerations in disclosing study results to research participants. Denver CO
- 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 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
- March 2009 **“Biobanks: Approaching Informed Consent for Continuing Research After Children Grow Up”** American College of Medical Genetics Annual Meeting. Tampa, FL
- March 2009 **“Revisiting the ASHG/ACMG Points to Consider: Why parents should have Authority to Consent on Behalf of their Children and adolescents may consent for themselves”** American College of Medical Genetics Annual Meeting. Tampa, FL
- May 2009 **Ethical Challenges in Pediatric Biobanks: Balancing Risks and Benefits.** Pediatric Academic Society Meeting. Baltimore MD
- Oct 2009 **“Ethical responsibilities regarding genetic testing for cancer susceptibility in children and family communication of genetic information to children”** American Society of Human Genetics Annual Meeting. Honolulu. HI

- Oct 2010 **“Ethical dilemmas in the management of “lethal” conditions: Lessons from Trisomy 13 & 18”** American Academy of Pediatrics National Conference and Exhibition, San Francisco, CA
- Oct 2010 **“Research Bioethics Consultation”** (Workshop Moderator) American Society of Bioethics and Humanities Annual Meeting, San Diego CA
- May 2010 **Ethical and Social Implications of providing intensive interventions to infant for whom clinical or developmental prognosis is uncertain.** (Topic Symposium Moderator) Pediatric Academic Societies Annual Meeting. Vancouver BC Canada
- May 2011 **“What does it mean to get assent from children in pediatric biobank genomic research”** Pediatric Academic Society Meeting. Denver CO
- May 2011 **“Assent for children enrolling in biobanks: Not “consent” for little adults”** Exploring the ELSI Universe. NHGRI. Chapel Hill, NC
- Oct 2011 **“Transforming clinical, parental, and society discord about disability: the example of trisomy 18 and 13”** (Panel moderator) American Society of Bioethics and Humanities Annual Meeting, Minneapolis, MN
- Oct 2012 **“Establishing Research Ethics Consultation: Core Features and tailored approaches”** (Workshop moderator) American Society of Bioethics and Humanities Annual Meeting, Washington DC
- Oct 2012 **“Social Work and Bioethics: A Call for Collaboration”**(Panel moderator) American Society of Bioethics and Humanities Annual Meeting, Washington DC
- Oct 2013 **“Genomic Testing in Children”**(Discussion moderator) Pediatrics and ELSI Affinity Group, American Society of Bioethics and Humanities Annual Meeting. Atlanta, GA
- Oct 2013 **“Why the SUPPORT Study was ethical”** Late-breaking Session. American Society of Bioethics and Humanities Annual Meeting. Atlanta, GA
- Oct 2013 **“Lessons from SUPPORT: Implications for Research on Medical Practice”** Cystic Fibrosis Therapeutic Development Network Annual Meeting. Salt Lake City, Utah
- Oct 2014 **“Research Bioethics Consultation and the CTSAs”**
“Articulating the Goals and Assessing the Impact of Bioethics Projects” American Society of Bioethics and Humanities Annual Meeting. San Diego, CA
- May 2014 **Accepting Brain Death.** Pediatric Academic Societies Annual Meeting. Vancouver BC Canada
- May 2014 **Lessons From SUPPORT: Opportunities to improve research in children by conducting research about the ethical concerns related to pediatric research.** Pediatric Academic Societies Annual Meeting. Vancouver BC Canada
- July 2014 **“Lessons from SUPPORT”** Association of Administrators in Academic Pediatrics Annual Meeting. Vancouver, BC
- April 2015 **“Ethical Complexities in Randomized Trials: Compared to what?”** Pediatric Academic Society Annual Meeting. San Diego, CA
- May 2015 **“Perspectives on Clinical Ethics and Consultation”**
“Research Ethics Consultation in the US: An Emerging role in Academic Medical Centers”

Annual 11th Annual International Conference on Clinical Ethics & Consultation
New York, NY

- Oct 2015 **“Using visual narrative in empirical bioethics research”**
“The Clinical Research Ethics Collaborative: a national network that discusses challenging cases and shares consultation practice approaches to promote ethical clinical research”
Association of Bioethics and Humanities Annual Meeting. Houston, TX
- April 2016 **“Ethical Complexities in Randomized Trials: Compared to what?”** Pediatric Academic Society Annual meeting. Baltimore, MD
- Oct 2016 **“Engaging stakeholders about research on medical practices in the learning health system: results of four empirical studies”** Association of Bioethics and Humanities Annual Meeting, Washington DC
- Nov. 2016 **“Research on Medical Practices (ROMP): Attitudes of IRB Professionals about Randomization and Informed Consent”**
“A Comparison of IRB Professionals’ and Patients’ Views on Research on Medical Practices (ROMP) “
Advancing Ethical Research, PRIMR, Anaheim, CA
- May 2017 **“State of the Art in Pediatric Genomics: Evidence from the CSER Consortium.”** Pediatric Academic Society Annual meeting. San Francisco, CA
- Nov. 2017 **“The role of research ethics consultation in IRB reviewed research: opportunities and challenges “**
Advancing Ethical Research, PRIMR, San Antonio, CA
- Oct 2018 **“Linguistic challenges in studying research on medical practice: the investigational misconception.”** Association of Bioethics and Humanities Annual Meeting, Anaheim CA

INVITED CONFERENCE PRESENTATIONS (selected, since 2005)

- Oct 2005 **“Bioethics, Excellence, and Physicians-in-Training”** AMSA Bioethics Conference. University of Arizona. Tucson AZ
- March 2005 **“Interpreting the definitions of risk in the federal research regulations”** Cystic Fibrosis Foundation Data Monitoring Committee Annual Meeting. Dallas TX
- 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

- May 2007 **“Disclosing Incidental Findings in Pediatrics”** Managing Incidental Findings in Human Subjects Research: From Imaging to Genomics, University of Minnesota., Minneapolis MN
- 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
- Feb 2008 **“Resolving conflicts in the ICU”** Pediatric Critical Care Symposium Wistler, BC, Canada
- July 2008 **“Tale of two cites: Genomics, ethics, and parental decision-making?”** Predicting our Future: Genetic Testing in Children and their Families. 4th Annual *Pediatric Bioethics Conference*. Treuman Katz Pediatric Bioethics Conference. 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
- 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
- April 2009 **“Ethical issues in Pediatric Research”** Washington State Society of Healthcare Attorneys Meeting. Seattle WA
- May 2009 **“Ethics of clinical data sharing”** Data sharing: Governance and Ethics in the CTSA environment: ITHS Workshop. Seattle WA
- July 2009 **“Newborn Screening and the Alpha one foundation approach”**(panel) Genetic Alliance Annual Meeting. Washington DC
- Sept 2009 **“Ethical issues that emerge during clinical research”** WIRB Annual Meeting. Seattle WA
- Oct 2009 **“Ethical issues that emerge during clinical research”** Quorum IRB Annual Meeting. Seattle WA
- March 2009 **“ Informed consent in clinical trials.”** Therapeutic Development Network Meeting. Cystic Fibrosis Foundation. Denver, CO
- March 2010 **“Don’t Ask, Don’t Tell: The ethics of learning to do medical procedures”** National Undergraduate Bioethics Conference. University of Puget Sound. Tacoma, WA
- May 2010 **“Introduction to Bioethics”** Undergraduate Biology Research Program Retreat. University of Arizona. Tucson, AZ
- Feb 2010 **“Identifying Common Ground and Potential Solutions”** (Panelist). ITHS Biorepository Development and Governance Workshop. Seattle WA
- Feb 2010 **“Ethical issues in research recruitment”**Protecting Research Participants: Ethical Challenges with in a Regulatory Framework (OHRP Community Forum). Seattle WA

- May 2011 **“Assent in Genomic Research”** Should we return individual research results and incidental findings from genomic biobanks and archives? University of Minnesota. Bethesda MD
- June 2011 **“Gene Discovery and ethics”**. Brain Development Conference. NeuroDevNet. Vancouver BC, Canada
- May 2012 **“Introduction to Bioethics”** Undergraduate Biology Research Program Retreat. University of Arizona. Tucson, AZ
- Oct 2012 **“Research with Children: Complex cases, Questions, and Conundrums”**. Achieving Excellence in Clinical Research: Scientific, Ethical, and Operational Considerations. Advocate Health. Chicago, IL
- Jan 2013 **“Mid Study ethical dilemmas: Disclosing results”** Seattle Nursing Research Workshop. Shoreline, WA
- Jan 2014 **“The Ethical Significance of the Research-Clinical Care Distinction”** Ethical Issues in Data Science. Mount Sinai School of Medicine. New York, NY
- Jan 2014 **“Ethical Issues in Comparative Effectiveness Research”** Seattle Nursing Research Workshop. Lynnwood, WA
- Nov 2014 **“Returning secondary research results of children to Families”** Should we offer genomic research results to participants family, including after death? University of Minnesota MN
- March 2015 **“The Cystic Fibrosis Newborn Screening Trial: An Ethical Precedent”** 7th Annual University of Wisconsin School of Medicine & Public Health Bioethics Symposium: Challenging the Norm: Fostering Ethics. Madison, WI
- Sept 2015 **“ROMP in the PARC: Research on Medical Practices- Public Attitudes about Research Consent”** Perinatal Research Society- 46th Annual Meeting, Engelwood CO.
- April 2015 **“ROMP in the PARC: Research on Medical Practices- Public Attitudes about Research Consent”** Cystic Fibrosis Foundation Therapeutics Data Safety and Monitoring Board Annual Meeting. Phoenix, AZ
- May 2016 **“A ROMP in the PARC: Research On Medical Practices - Public Attitudes for Research Consent”** Consent Quorum IRB Seattle, WA
- May 2016 **“A ROMP in the PARC: Research On Medical Practices - Public Attitudes for Research Consent”** Tenth Annual Chapel Hill Pharmaceutical Sciences Conference. Chapel Hill, NC
- May 2016 **“Ethical Considerations in Treating Cardiovascular Disease in Children with Trisomy”** Western Society of Pediatric Cardiology Annual Conference, Salt Lake City, Utah
- Aug 2016 **“Basics of Ethics Committees”** – 29th Annual Summer Seminar in Health Care Ethics, The University of Washington School of Medicine, Department of Bioethics and Humanities, Seattle, Washington
- Aug 2017 **“Ethics Consultation”** – 30th Annual Summer Seminar in Health Care Ethics, The University of Washington School of Medicine, Department of Bioethics and Humanities, Seattle, Washington

- Aug 2018 **“Ethics Consultation”** – 30th Annual Summer Seminar in Health Care Ethics, The University of Washington School of Medicine, Department of Bioethics and Humanities, Seattle, Washington
- Sept 2018 **“Ethical considerations in providing cardiac surgery for children with Trisomy 18”** – Advances in Fetology 2018, Atlanta, GA
- INVITED WORKSHOP PRESENTATIONS (selected, since 2005)
- Feb 2005 **“Ethical issues in newborn screening research”** Fragile X Study Group, University of North Carolina. Chapel Hill, NC
- 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
- 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 2009 **“Research on residual newborn screening blood spots”** March of Dimes Bioethics Advisory Committee Meeting White Plains NY.
- Aug 2009 **“Approaching informed consent after children grow up”** Fred Hutchison Cancer Center IRB Informed Consent Working Group. Seattle WA
- May 2011 **“Policy approaches to Recruitment “** Workshop on Ethical Approaches to Genotype Driven Research Recruitment. Duke University. Raleigh, NC
- Nov 2011 **“Wisconsin Cystic Fibrosis study and undisclosed findings”**. Unanticipated Findings in Newborn Screening. NBSTRN Bioethics and Legal Issues Workgroup. American College of Medical Genetics. Bethesda, MD
- June 2012 **“Returning incidental findings to parents”**. Disclosing Genomic Incidental Findings in Cancer Biobank. Working Group. Minneapolis, MN
- May 2013 **“Genetic Sequencing in Children”** Bioethics Advisory Committee. March of Dimes. White Plains, NY
- Sept 2013 **“Ethical issues in research about the use of psychotropic drugs in children”**. Workshop on the use of psychotropic drugs in children. University of British Columbia. Vancouver BC, Canada
- March 2015 **“Ethical frameworks for policy decisions about newborn screening”** Newborn Screening Advisory Committee. Washington Department of Health Shoreline, WA.
- Feb 2015 **“Clinical Research Interactions”** Regional Centers for Excellence in ELSI Research Meeting. Seattle, WA.
- Nov 2016 **“The development of Research ethics consultation”** Neuroscience and Ethics Engagement: From Gray Matters to an NSF Engineering Research Center, Center for Sensorimotor Neural Engineering, University of Washington, Seattle, WA
- Jan 2018 ***“improving informed consent: lessons from empirical ethics research”*** ITHS. Seattle, Wa

GRAND ROUNDS/INVITED LECTURES (since 2000)

- June 2000 **“Bioethics: a new medical specialty”** Anesthesia Grand Rounds, Boston Children’s Hospital. Boston, MA April 2004 **“Ethics and excellence: getting to the top of the hill”**, AOA Induction Keynote Address, New Jersey Medical School, Newark, NJ
- Feb 2002 **“Cystic fibrosis newborn screening”** Department of Pediatrics Grand Rounds. Columbia University. New York, NY
- March 2004 **“Direct to consumer advertising for genetic tests”** Pediatric Grand Rounds, University of Wisconsin Department of Pediatrics. Madison, WI
- March 2003 **“The Commercialization of Genetics”** Inaugural RJ Fellowship Symposium, Muhlenberg College. Allentown, PA
- April 2003 **“Gene therapy and research in children”** Pediatric Grand Rounds, University of Colorado. Denver, CO
- May 2005 **“Ethical issues in Pediatric Research”** 17th Annual Stuart Stevenson Lecture. UMDNJ-New Jersey Medical School, Newark, NJ
- 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
- 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.
- Dec 2010 **Direct to Consumer Marketing of Genomics: Ethical, (Legal) and Social Implications.** Institute of Translational health Sciences Interdisciplinary Grand Rounds. University of Washington. Seattle, WA
- Dec 2010 **“Technological interventions in children with profound disabilities: Balancing children’s interests, parental preferences, and resource constraints”** Pediatric Grand Rounds. Arkansas Children’s Hospital, Little Rock, AR
- Jan 2012 **Technological interventions in children with profound disabilities: Balancing children’s interests, parental preferences, and resource constraint.** Grand Rounds, Rady Childrens Hospitals San Diego, CA
- March 2012 **“Technological interventions in children with profound disabilities: Balancing children’s interests, parental preferences, and resource constraint.”** Program for Medical Ethics, Yale School of Medicine, New Haven, CT
- Dec 2013 **“Ethical issues in comparative effectiveness research: Lessons from the support trial of high vs low oxygen saturations in premature newborns”**(with Ruth Macklin) Forum, Division of Medical Ethics, Harvard Medical School, Boston, MA
- Dec 2013 **“Ethical issues in comparative effectiveness research: Lessons from the support trial of high vs low oxygen saturations in premature newborns”**(with Ruth Macklin) Medicine Grand Rounds. Beth Israel-Deconess Medical Center. Boston, MA

- Jan 2014 **“Lessons from SUPPORT: Ethical Implications of Research on Medical Practice”** Lieken Lecture, Pediatrics Grand Rounds, Children’s National Medical Center, Washington DC
- Jan 2014 **“Involving Children in research on Psychotropic Medications”** Psychiatry Grand Rounds, Children’s National Medical Center, Washington DC
- Feb 2014 **“Informed consent for research blood collection in stem-cell transplant patients”**. Grand Rounds, Fred Hutchison Cancer Research Center, Seattle, WA
- Oct 2014 **“Ethical Aspects of Clinical Trials: compared to what?”** 9th Annual Cynthia Stolman Lectureship, Department of Pediatrics. Rutgers- New Jersey Medical School
- March 2015 **“ROMP in the PARC: Research on Medical Practices- Public Attitudes about Research Consent”** Grand Rounds, Sacred Heart Medical Center. Spokane, WA
- April 2015 **“Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values”** Medearis Lecture-Pediatric Grand Rounds. University of Pittsburgh. Pittsburgh, PA
- April 2015 **“ROMP in the PARC: Research on Medical Practices- Public Attitudes about Research Consent”** Emerson Lecture in Medical Ethics. Trent Center for Bioethics, Humanities & History of Medicine, Duke University. Raleigh, NC
- June 2015 **“ROMP in the PARC: Research on Medical Practices- Public Attitudes about Research Consent”** Pediatric Grand Rounds. St Jude Children’s Research Hospital, Memphis, TN
- July 2015 **“Changing Ethical Paradigms for the Treatment of Children with Trisomy 18”** Pediatric Grand Rounds. Primary Children’s Hospital. Salt Lake City, UT
- Nov 2015 **“Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values”** Christine Harrison Lecture in Pediatric Bioethics, Pediatric Grand Rounds, Hospital for Sick Children. Toronto, ON, CA
- Feb 2016 **“A ROMP in the PARC: Research on Medical Practices - Public Attitudes for Research Consent”** Bioethics Grand Rounds, Department of Bioethics and Humanities, University of Washington School of Medicine, Seattle WA
- March 2016 **“Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values”** Webinar. Children’s Mercy Bioethics Center Kansas City, MO
- June 2016 **“A ROMP in the PARC: Research On Medical Practices - Public Attitudes for Research Consent”** Integrated Research Center for Fetal Medicine. Johns Hopkins University, Baltimore, MD
- August 2016 **“Technological Interventions in Children with Profound Disabilities: Navigating Family & Professional Values”** Egleston Research Grand Rounds, Emory + Children’s Pediatric Research Center, Atlanta, GA

May 2017

“A ROMP in the PARC: Research On Medical Practices - Public Attitudes for Research Consent” Pediatrics Grand Rounds. University of North Carolina Chapel Hill, Chapel Hill, NC