## **CURRICULUM VITAE**

### **BIOGRAPHICAL**:

Name: Alan Edward Guttmacher

Work Address: (Effective December 1, 2009)

Eunice Kennedy Shriver National Institute of Child Health and Human

Development

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**Present Position:** (Effective December 1, 2009)

**Acting Director** 

Eunice Kennedy Shriver National Institute of Child Health and Human

Development

National Institutes of Health

**EDUCATION**:

1967-1972 A.B. cum laude in Social Relations, Harvard University

1975 Pre-medical student, Johns Hopkins University

1975-1976 Pre-medical student, Duke University

1977-1981 M.D., Harvard University

#### **POSTGRADUATE TRAINING:**

1981-1982	Physician, Developmental Pediatrics Clinics, Children's Hospital, Boston
1982-1985	Intern and Resident in Pediatrics, Children's Hospital, Boston
1985-1987	Fellow in Medical Genetics, Children's Hospital, Boston and Harvard Medical School

#### **APPOINTMENTS AND POSITIONS (POST-TRAINING):**

1987-1999	Director, Vermont Regional Genetics Center and Pregnancy Risk Information
	Service, University of Vermont College of Medicine
1987-1993	Assistant Professor of Pediatrics, University of Vermont College of Medicine

1989-1999	Founding Medical Director, Vermont Newborn Screening Program
1991	Founding Director, Pediatric Intensive Care Unit, Medical Center Hospital of Vermont
1993-1996	Tenured Associate Professor of Pediatrics, University of Vermont College of Medicine
1993-1999	Founding Director, Familial Cancer Program, Vermont Cancer Center, University of Vermont College of Medicine
1995-1999	Founding Director, Vermont Human Genetics Initiative, University of Vermont College of Medicine
1996-1999	Tenured Associate Professor of Pediatrics and Medicine, University of Vermont College of Medicine
1999-2002	Senior Clinical Advisor to the Director, National Human Genome Research Institute, National Institutes of Health
2002-2008	Director, Office of Policy, Communication, and Education, National Human Genome Research Institute, National Institutes of Health
2002-Present	Deputy Director, National Human Genome Research Institute, National Institutes of Health
2008-2009	Acting Director, National Human Genome Research Institute, National Institutes of Health
2009-Present	Acting Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development

# **OTHER POST-BACCALAUREATE EMPLOYMENT:**

1972	Housepainter, Cambridge, MA
1972	County Coordinator, McGovern-Shriver Campaign, LaSalle County, IL
1972-1973	Laborer, Dayton Dairy Co., Dayton, IL
1973-1975	Middle School Humanities Teacher, Park School, Brooklandville, MD
1976-1977	Junior Executive, Blue Hill Memorial Hospital, Island Medical Center, and Four- Town Home Health Agency, Hancock County, ME

# **LICENSURE**:

1981-1987 Massachusetts

1987-1998 New York

1987-Present Vermont

# **BOARD CERTIFICATION**:

1987-Present American Board of Medical Genetics, Diplomate and Certification in Clinical

Genetics

1989-1996 American Board of Pediatrics, Diplomate

# **HOSPITAL APPOINTMENTS**:

1986-1987	Senior Associate in Pediatrics, Beth Israel Hospital, Boston, MA
1987-1999	Attending in Pediatrics, Medical Center Hospital of Vermont, Burlington, VT
1987-1999	Referring Consulting Staff, Champlain Valley Physicians Hospital, Plattsburgh, NY
1996-1999	Medical Staff, Rutland Regional Medical Center, Rutland, VT
2002-Present	Medical Staff, Clinical Center, National Institutes of Health

# **AWARDS AND HONORS**:

1978-1981	National Health Service Corps Scholarship, U.S. Public Health Service
1985-1986	Farley Fellowship, Children's Hospital, Boston
1985-1987	National Research Service Award, U.S. Public Health Service
1989	Volunteer of the Year, Vermont Chapter, March of Dimes Birth Defects Foundation
1990	Elected to Membership, Alpha Omega Alpha Medical Honorary Society
1996	Volunteer of the Year, Hereditary Hemorrhagic Telangiectasia Foundation International
1999	Honorable Mention, American Medical Women's Association Gender Equity Award, University of Vermont
2000	Joseph E. Cannon Award, New England Public Health Association
2000	Commencement Speaker, University of Vermont College of Medicine
2000	Presidential Lecturer, The Endocrine Society, Toronto, Canada
2000	State of the Art Lecturer, The First World Congress of Pediatric Gastroenterology
2000	Presidential Lecturer, Annual Conference, American Dietetic Association
2000	Kozinn Lecturer, Maimonides Medical Center
2001	Beth Fine Kaplan Memorial Lecture, Department of Obstetrics & Gynecology, Northwestern University Medical School
2001	Sommer Lecturer, Oregon Health Sciences University

2001	Distinguished Lecturer, Annual Education Awards Ceremony, Baylor College of Medicine
2001	Laurell Lecturer, 3 <sup>rd</sup> International Scientific Conference on Alpha 1-Antitrypsin Deficiency
2001	Mary E. Switzer Lecturer, The Association of Schools of Allied Health Professions
2001	Award of Merit, National Institutes of Health
2002	President's Distinguished Lecturer, Society for Gynecologic Investigation
2002	Edward Penn Memorial Lecturer, Annual Meeting, Massachusetts Chapter, American Academy of Pediatrics
2002	Jerome Cochran Lecturer, Annual Meeting, Medical Association of the State of Alabama
2003	Ellwood Lecturer, Annual Conference, Uniform Services Section, American Academy of Pediatrics
2003	Presidential Scholar Lecturer, Association for Behavior Analysis
2003	Secretary's Award for Distinguished Service, U.S. Department of Health and Human Services
2003	Award of Merit, National Institutes of Heath
2004	Roland B. Scott Lecturer, Annual Meeting, National Sickle Cell Disease Program
2004	Elected to Membership, Institute of Medicine
2006	Scientific Leadership Award, Hereditary Hemorrhagic Telangiectasia Foundation International
2006	Secretary's Award for Distinguished Service, U.S. Department of Health and Human
2006	Director's Group Award, National Institutes of Health
2009	The Surgeon General's Certificate of Appreciation

# **PROFESSIONAL SOCIETIES**:

1987-1999	Member, Vermont State and Chittenden County Medical Societies
1987-Present	Member, American Society of Human Genetics
1989-1999; 2007-Present	Member, American Public Health Association
1990-1998; 2002-Present	Fellow, American Academy of Pediatrics; Member, Section on Genetics
1991-1994	Member, International Society for Neonatal Screening

1997-Present Fellow, American College of Medical Genetics

2004-Present Member, Institute of Medicine

# **INSTITUTIONAL COMMITTEES**:

1988-1999	Promotion and Tenure Committee - Department of Pediatrics, University of Vermont
1989	Subcommittee on Clinical Science Departments, Medical College Institutional Self-Study, University of Vermont College of Medicine
1992	Primary Care Initiatives Committee, University of Vermont College of Medicine
1993	Committee to Assess Pediatric Care, Medical Center Hospital of Vermont
1994-1999	Department of Pediatrics Research Working Group, University of Vermont
1995-1997	Primary Care Development Committee, University of Vermont College of Medicine
1996-1999	Vermont Cancer Center, University of Vermont College of Medicine
1996-1999	General Clinical Research Center Advisory Committee, University of Vermont College of Medicine (Chair, 1998-1999)
1998-1999	Curriculum Redesign Committee, University of Vermont College of Medicine
1999-2008	Executive Committee, National Human Genome Research Institute
1999-2000	National Human Genome Research Institute liaison to Genetics Education Committee, National Cancer Institute
1999-2000	National Human Genome Research Institute liaison to Cancer Genetics Network Family History Working Group, National Cancer Institute
1999-2000	Blue Ribbon Panel on Genetic Technologies, National Conference of State Legislatures
1999-2003	National Human Genome Research Institute liaison, National Coalition for Health Professional Education in Genetics
2000-2001	Subcommittee on Insurance Coverage issues, National Conference of State Legislatures
2000-2009	National Institutes of Health liaison, Association of Professors of Human and Medical Genetics
2000-2002	Rare Disease Working Group, Secretary's Advisory Committee on Genetic Testing
2001-2003	Executive Committee, Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program
2001-2006	Minority Outreach Team, National Human Genome Research Institute
2002-2003	Co-chair, April 2003 Committee, National Human Genome Research Institute

2002-2003	Steering Committee, Long-Range Planning Process, National Human Genome Research Institute
2002	Advisory Committee, National Human Genome Research Institute/Office of Rare Diseases Information Center
2002-2003	Co-chair, Trans-NIH Planning Committee on Genetic, Behavioral, and Social Factors in Health
2002-2006	National Human Genome Research Institute liaison, National Institutes of Health Prevention Research Coordinating Committee
2002-2005	Diabetes Mellitus Interagency Coordinating Committee, National Institutes of Health
2002-2009	National Human Genome Research Institute liaison, National Children's Study, National Institutes of Health
2002	Behavioral/Social Science Search Committee, National Human Genome Research Institute
2002-2009	National Human Genome Research Institute liaison, Trans-NIH Rare Diseases Working Group
2002	Scientific Director Search Committee, National Human Genome Research Institute
2002-2003	National Human Genome Research Institute liaison, Committee on Genetics National Human Research Protections Advisory Committee
2003-2008	Co-chair, Trans-NIH Sickle Cell Disease Research Working Group
2003-2009	National Human Genome Research Institute liaison, NIH Obesity Research Task Force
2003-2006	Alternate, Public Health Service Technology Transfer Board
2004-2005	National Human Genome Research Institute liaison, Digestive Diseases Interagency Coordinating Committee Liver Disease subcommittee
2004	Member, Qualifications Review Board, National Science Advisory Board for Biosecurity Executive Director search
2004-2005	National Human Genome Research Institute representative, Public Trust Liaison Group
2004-2007	Trans-NIH Sarcoidosis Working Group
2004-2005	AIDS Coordinator, National Human Genome Research Institute
2006-2009	Medical Director and Member of Executive Committee, Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program
2006	Chair, Organizing Committee, "Hereditary Hemorrhagic Telangiectasia: Vascular Biology and Pathophysiology" meeting

2007	Chair, Organizing Committee, First International Chordoma Research Workshop
2007	Chair, Organizing Committee, Physician Assistants and Genomics Meeting
2007-Present	Co-Chair, NIH Advisory Committee on Ethics Regulation Implementation
2007-2008	Chair, Search Committee, Deputy Director, Clinical and Translational Research, National Center for Research Resources, NIH
2008-2009	Member, Office of Portfolio Analysis and Strategic Initiatives Working Group
2008-2009	Co-Chair, NIH Genome Wide Association Studies Senior Oversight Committee
2008-2009	Co-Chair, Genotype-Tissue Expression Initiative Implementation Group, NIH Roadmap for Medical Research
2008-2009	NIH representative, Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS)
2009	Member, NIH Ad Hoc Challenge Grant Applications Committee
2009	Co-Chair, American Recovery and Reinvestment Act Sequencing Coordinating Committee
2009	Member, NIH Associate Director for Legislative and Policy Analysis Search Committee
2009-Present	Member, NIH Bioethics Task Force

## **JOURNAL DUTIES:**

Co-editor: Series on Genomic Medicine in *The New England Journal of Medicine*, 2002-2003 Series on Genomics in Medicine in *The New England Journal of Medicine*, 2010-2011

Ad Hoc Reviewer: Pediatrics, The New England Journal of Medicine, Journal of Hepatology,
Digestive Diseases, Thrombosis and Haemostasis, American Journal of
Medical Genetics, Human Genetics, Nature, JAMA

## **OTHER PROFESSIONAL ACTIVITIES:**

1987-1995	Vermont Chapter, March of Dimes Birth Defects Foundation: Executive Committee (1987-1991); Health Professionals Advisory Committee (1987-1995; Chair, 1987-1989)
1987-1999	Advisory Committee on Newborn Screening, Vermont Department of Health
1987-1998	New England Regional Genetics Group: Steering Committee (1987-1989); Prevalence Committee (1987-1998); Grant Review Committee (1987-1989)
1988-1999	Planned Parenthood of Northern New England - Board of Directors (1988-1995); Vice-President (1990-1992); President (1992-1994); Medical Practices Committee

	(1990-1995); Executive Director Search Committee (1995); Honorary Member, Board of Directors (1997-1999)
1989-1991	Vermont Department of Health, Committee on Substance Abuse in Pregnancy
1990-1993	Pediatrician, Vermont Special Olympics
1990-1999	Advisory Board, <u>Beyond Affliction</u> (Documentary radio and film project)
1990-1991	Advisor, Chittenden County Kid's First
1992-1999	Board of Directors, the Alan Guttmacher Institute, New York, NY; First Vice Chair (1995-1998); Chair (1998-1999)
1992-1999	Advisory Board, Hood Center for Caregiving Families
1993-Present	Scientific and Medical Advisory Board, Hereditary Hemorrhagic Telangiectasia Foundation International, Inc.
1995-1999	Board of Directors, Planned Parenthood Federation of America, New York, NY
1998-2001	Blue Ribbon Panel on Genetic Technologies and Subcommittee on Insurance, National Conference of State Legislatures
1999-2004	Acting coordinator, Genetics Resources on the Web (GROW)
1999	Interim Acting Executive Director, National Coalition for Health Professional Education in Genetics
1999-2004	National Human Genome Research Institute liaison to Federal Interagency Genetics Working Group
1999-2005	National Human Genome Research Institute liaison to Public Health Genetics Committee, American College of Medical Genetics
2000	National Human Genome Research Institute liaison to Long Range Planning Process, American College of Medical Genetics
2000-2001	Organizing Committee, Harvard Conference on Educating Medical Students about Genetics
2000-2002	Rare Disease Working Group, Secretary's Advisory Committee on Genetic Testing, U.S. Department of Health and Human services
2001-2003	National Human Genome Research Institute liaison to Annual Clinical Focus project, American Academy of Family Physicians
2001	Research Planning and Evaluation Committee, American Heart Association
2001-2006	National Human Genome Research Institute liaison to Bureau of Health Professions, Health Resources Services Administration
2001-2005	National Human Genome Research Institute liaison to Medical Operations Branch, National Aeronautics and Space Administration
2001-2002	Institute of Medicine Committee on Educating Public Health Professionals for the

	21st Century
2001	External curriculum review of the Summer Genetics Institute, National Institute of Nursing Research
2001-2005	Pharmacogenetics Research Network Human Subjects Committee
2002	Panel on Genetics Education, Association of American Medical Colleges
2002	GENE Advisory Committee, March of Dimes
2002	Steering Committee, Workshop on application of information technology to the transformation of clinical research and health care in the 21st century, Association of American Medical Colleges
2004-2008	Member (Chair, 2004-2006), Research Grants Committee, HHT Foundation, International
2004-2008	Chair, U.S. Surgeon General's Family History Initiative Working Group
2005	Member, Conference Planning Committee, National Academies/Keck Futures Initiative meeting on "The Genomics Revolution: Implications for Science and Health"
2005-2008	Member, Advisory Board, Intermountain Health Care Clinical Genetics Institute
2005	Member, Task Force on Genetics Screening, the American College of Obstetricians and Gynecologists
2005-2008	Member, Awards Committee, Outstanding Medical Geneticist, Harvard Medical School-Partners HealthCare Center for Genetics and Genomics
2006	Member, Organizing Committee, Cold Spring Harbor Laboratory - Sanger Centre Pharmacogenomics Meeting
2006-2008	Member, Project Oversight Committee,
	Advisory Panel on New Science and Technology, United States Pharmacopeia
2006-2008	Member, American Health Information Community Personalized Health Care Workgroup; Co-Chair, Family History Subgroup
2007-2008	Member, Institute of Medicine Roundtable on Translating Genomic Based Research for Health
2007	Member, External Peer Review Panel, National Office of Public Health Genomics, Centers for Disease Control and Prevention
2008-2009	Member, Genomic Medicine Program Advisory Committee, U.S. Department of Veterans Affairs
2009	Executive Committee, International Cancer Genome Consortium

2009-Present NIH representative, Interagency Coordinating Committee (IACC) for Autism

#### OTHER INVITED NATIONAL/INTERNATIONAL PARTICIPATION (Partial Listing):

- 1991 Faculty member Massachusetts General Hospital Teratology Review Course, Boston, MA
- 1991 Member International Organizing Committee, Beijing International Conference on Neonatology, Beijing, China
- 1992 Discussant Annual Conference, HHT Foundation International, Columbus, OH
- 1992 Moderator Session on Clinical Genetics, Annual Meeting, American Society of Human Genetics, San Francisco, CA
- 1993 Presenter Annual Conference, HHT Foundation International, San Francisco, CA
- 1993 Witness United States Senate Committee on Labor and Human Resources, Hearing on Health Care Reform, Brattleboro, VT
- 1994 Presenter Annual Conference, HHT Foundation International, Boston, MA
- 1995 Moderator Annual Conference, HHT Foundation International, Chicago, IL
- 1995 Presenter Primary Care Review Program, Temple University School of Medicine, Lancaster, PA
- 1996 Presenter/Panelist Primary Care Provider Genetics Education Workshop, Council of Regional Genetics Networks/Maternal and Child Health Bureau/Health Resources and Services Administration, Bethesda, MD
- 1996 Member, Organizing Committee and Session Chair Rendu Centenary Meeting, Edinburgh, Scotland
- 1996 Moderator and Presenter Annual Conference, HHT Foundation International, Salt Lake City, UT
- 1996 Lecturer Annual Gorlin Dysmorphology Conference, Minneapolis, MN
- 1997 Presenter Workshop on Medical Genetics Education in Primary Care Resident Training, Bureau of Health Professions/Maternal and Child Health Bureau, Bethesda, MD
- 1997 Participant Conference on Provision of Genetics Services, Josiah Macy, Jr. Foundation, Williamsburg, VA
- 1997 Member of Organizing Committee, Session Chair and Presenter Workshop on Hereditary Hemorrhagic Telangiectasia: A Disorder of the Vasculature, National Heart, Lung and Blood Institute, Bethesda, MD
- 1997 Moderator and Presenter Annual Conference, HHT Foundation International, Atlanta, GA
- 1997 Member of Organizing Committee, Session Chair, and Presenter Hereditary Hemorrhagic Telangiectasia Scientific Conference, Curacao, Netherland Antilles

- 1997-8 Member, Organizing Committee Conference on Education of Health Care Professionals in Genetics, Josiah Macy, Jr. Foundation
- 1998 Interviewee Beyond Affliction (radio documentary), National Public Radio
- 1998 Interviewee Talk of the Nation, National Public Radio
- 1998 Lecturer Association of Reproductive Health Professionals, St. Louis, MO
- 1999 Lecturer Society for General Internal Medicine Course on Genetics, San Francisco, CA
- 1999 Featured Speaker Medical Technology & Quality Health Care: A 21<sup>st</sup> Century Perspective, National Committee for Quality Health Care, Chicago, IL
- 1999 Keynote Speaker Human Genome Education Model Project II, Arlington, VA
- 1999 Keynote Speaker Georgia Public Health Association Annual Meeting, Savannah, GA
- 1999 Featured Speaker National Association of Biology Teachers, Ft. Worth, TX
- 1999 Panelist Alliance of Genetic Support Groups Annual Meeting, Arlington, VA
- 1999 Speaker National Health Council Strategic Planning Session, Washington, DC
- 1999 Keynote Speaker Conference for State Legislators sponsored by Maternal and Child Health Bureau, Lake Buena Vista, FL
- 2000 Keynote Speaker Conference of Planned Parenthood Federation of America, Marco Island, FL
- 2000 Lecturer, Conference of the Queen's Medical Center, Honolulu, HI
- 2000 Keynote Speaker, College of American Pathologists Leadership and Government Affairs Conference, Washington, DC
- 2000 Keynote Speaker, Washington Psychiatric Society, Washington, DC
- 2000 Keynote Speaker, Spring Meeting, Association of American Medical College's Council of Academic Societies, Savannah, GA
- 2000 Speaker, Annual Meeting, American College of Physicians American Society of Internal Medicine, Philadelphia, PA
- 2000 Keynote Speaker, Board of Regents/Board of Governors, American College of Physicians American Society of Internal Medicine, Philadelphia, PA
- 2000 Speaker, Association of Professors of Human and Medical Genetics, Annual Workshop, Clearwater, FL
- 2000 Keynote Speaker, the Healthcare Assembly, Boston, MA
- 2000 Keynote Speaker, Annual Meeting, American Association of Clinical Endocrinologists, Atlanta, GA
- 2000 Speaker, Association for Clinical Pastoral Education, Annual Meeting, Bethesda, MD
- 2000 Keynote Speaker, New England Public Health Association Annual Educational Conference

- and Meeting, Durham, NH
- 2000 Keynote Speaker Conference for State Executive Department leaders sponsored by Maternal and Child Health Bureau, Rensselaerville, NY
- 2000 Speaker, Annual Meeting, Association of Medical School Psychologists, Washington, DC
- 2000 Speaker, Genetic Competencies in Public Health Meeting, Centers for Disease Control and Prevention, Atlanta, GA
- 2000 Speaker, Federation of State Medical Boards, Arlington, VA
- 2000 Plenary Speaker, Annual Meeting, MedChi, the Maryland State Medical Society, Ocean City, MD
- 2000 Keynote Speaker, Genetics and the Law Conference Sponsored by the Einstein Institute for Science, Health and the Courts and the National Institute of Environmental Health Sciences, Chapel Hill, NC
- 2000 Speaker, West Virginia Hospital Association Annual Meeting, White Sulphur Springs, WV
- 2000 Moderator, Speaker, Sessions of the Annual Meeting of the American Society of Human Genetics, Philadelphia, PA
- 2000 Grand Rounds Speaker, Department of Family Medicine, Jefferson Medical College, Philadelphia, PA
- 2000 Speaker, American Academy of Insurance Medicine, Annual Scientific Conference, Indianapolis, IN
- 2000 Speaker, Conference on "American Healthcare: Current Challenges and Drivers of Change, Harvard School of Public Health," Boston, MA
- 2000 Speaker, American Public Health Association, Boston, MA
- 2000 Speaker, Conference of the Pharmaceutical Education & Research Institute, Inc., Arlington, VA
- 2000 Speaker, Army and Navy Chapters of the American College of Physicians, Reston, VA
- 2000 Keynote Speaker, Annual Meeting, American College of Clinical Pharmacy, Los Angeles, CA
- 2000 Keynote Speaker, Annual Meeting, American Society of Health-system Pharmacists, Las Vegas, NV
- 2001 Speaker, John F. Kennedy School of Government/Commonwealth Fund Bipartisan Congressional Health Policy Conference, Aventura, FL
- 2001 Participant, Human Genome Epidemiology Workshop, Atlanta, GA
- 2001 Speaker/Participant, Banbury Center Conference on "Integrating Genomics Technologies in Healthcare: Practice and Policy Challenges," Cold Spring Harbor Laboratory, NY
- 2001 Speaker, Annual Meeting, American Clinical Laboratory Association, Washington, DC

- 2001 Plenary Speaker, the National Leadership Conference, American Medical Association, Washington, DC
- 2001 Keynote Speaker, Graduation Ceremony for Program in Genetic Counseling, Northwestern University Medical School, Chicago, IL
- 2001 Speaker, Meeting of Board of Directors, American Academy of Family Physicians, Washington, DC
- 2001 Plenary Speaker, Medical Research Summit, Health Care Compliance Association, Washington, DC
- 2001 Speaker, National Conference, Association of Health Care Journalists, Atlanta, GA
- 2001 Plenary Speaker, Annual Meeting, Association of Maternal and Child Health Programs, Washington, DC
- 2001 Speaker, American College of Osteopathic Family Physicians, Philadelphia, PA
- 2001 Keynote Speaker, Vermont Emergency Medical Services Annual Conference, Burlington, VT
- 2001 Speaker, Strategic Planning and Policy Committee, American Hospital Association, Chicago, IL
- 2001 Plenary Speaker, American Gastroenterological Association, Atlanta, GA
- 2001 Keynote Speaker, American Industrial Hygiene Conference and Exposition, New Orleans, LA
- 2001 Panel Moderator, The People's Genome Celebration, The Genetic Alliance, Washington, DC
- 2001 Grand Rounds Speaker, the Children's Hospital, Boston, MA
- 2001 Plenary Speaker, American Association of Medical Society Executives, Washington DC
- 2001 Plenary Speaker, Association of State and Territorial Health Officials Senior Deputies, Wilmington, DE
- 2001 Keynote Speaker, Dorsey Hughes Symposium, Beaver Creek, CO
- 2001 Speaker, HHT Foundation, International Annual Conference, Anaheim, CA
- 2001 Grand Rounds Speaker, Department of Pediatrics, Uniformed Services University of the Health Sciences, Bethesda, MD
- 2001 Speaker, the Ontario Provincial Advisory Committee on New Predictive Genetic Technologies, Toronto, Canada
- 2001 Plenary Speaker, Annual Meeting, Institute of Home Office Underwriters, Los Angeles, CA
- 2001 Plenary Speaker, Annual Conference, American Association of University Affiliated Programs, Bethesda, MD
- 2001 Keynote Speaker, Twentieth Annual Health Executive Forum, Scottsdale, AZ

- 2001 Plenary Speaker, National Institutes of Health Public Forum, the East-West Center, University of Hawaii, Honolulu, HI
- 2001 Grand Rounds, The Queen's Medical Center, Honolulu, HI
- 2001 Keynote Speaker, Human Genome Conference, Prince George's Community College, Largo, MD
- 2001 Keynote Speaker, Leadership Meeting, American Association on Mental Retardation, Washington, DC
- 2001 Plenary Speaker, Annual Meeting, Federation of Behavioral, Psychological, and Cognitive Sciences, Washington, DC
- 2001 Plenary Speaker, Project on "Judaism and Genetics," American Association for the Advancement of Sciences, Washington, DC
- 2001 Speaker, Second Tuesday Breakfast Club, Washington, DC
- 2002 Plenary Speaker, 2002 National Health Policy Conference: Shared Power, Shared Responsibility, co-sponsored by *Health Affairs* and the Academy for Health Services Research and Health Policy, Washington, DC
- 2002 Speaker, Annual Meeting, American Academy of Sciences, Boston, MA
- 2002 Keynote Speaker, Annual Meeting, California Academy of Family Physicians, San Francisco, CA
- 2002 Plenary Speaker, Medical Research Summit, Health Care Compliance Association, Washington, DC
- 2002 Keynote Speaker, Opening of the Helen F. Graham Cancer Center, Wilmington, DE
- 2002 Keynote Speaker, Annual Conference, National Association of Perinatal Social Workers, Stowe, VT
- 2002 Keynote Speaker, Annual Meeting, Association of State and Territorial Nursing Directors, Charleston, SC
- 2002 Speaker, School of Public Health and Community Medicine, University of Washington, Seattle, WA
- 2002 Keynote Speaker, Emerging Technologies & Healthcare Innovations Congress, Washington, DC
- 2002 Keynote Speaker, Meharry Medical College, Faculty Development Retreat, Nashville, TN
- 2002 Keynote Speaker, American Association of Health Plans Medical Management Forum, Chicago, IL
- 2002 Keynote Speaker, Annual Conference, National Organization for Rare Disorders, Arlington, VA
- 2002 Keynote Speaker, Annual International Conference, International Society of Nurses in Genetics, Baltimore, MD

- 2002 Keynote Speaker, Annual Meeting, Medical Decision Making Society, Baltimore, MD
- 2003 Speaker, Congressional Foresight Seminar, Washington DC
- 2003 Keynote Speaker, Annual Conference in Science & Engineering, The Graduate Center of the City University of New York, New York, NY
- 2003 Keynote Speaker, the Clinical Application of Genomics Workshop, Medical College of Wisconsin, Milwaukee, WI
- 2003 Keynote Speaker, Conference on Genetics, Disability and Deafness, Gallaudet University, Washington, DC
- 2003 Plenary Speaker, Oncology Nursing Society, Annual Meeting, Denver, CO
- 2003 Plenary Lecturer, American Association of Physician Assistants, New Orleans, LA
- 2003 Plenary Speaker, American College of Osteopathic Medicine, Bethesda, MD
- 2003 Plenary Speaker, Conference on Teaching the Genetics of Complex Diseases in Clinical Clerkships, Harvard Medical School, Boston, MA
- 2003 Plenary Speaker, 4th World Congress on Pediatric Intensive Care, Boston, MA
- 2003 Grand Rounds Speaker, University of Mississippi Medical Center
- 2003 Plenary Speaker, Symposium on the Functional Genomics of Critical Illness and Injury, Bethesda, MD
- 2003 Plenary Speaker, Hot Topics in Neonatology, Washington, DC
- 2004 Session Chair, Organization for Economic Cooperation and Development Workshop on Human Genetic Research Databases: Issues of Privacy and Security, Tokyo, Japan
- 2004 Speaker, American Society for Experimental NeuroTherapeutics, Bethesda, MD
- 2004 Plenary Speaker, Council of Deans, American Association of Medical Colleges, Key Biscayne, FL
- 2004 Plenary Speaker, Annual National Birth Defects Prevention Conference, National Center on Birth Defects and Developmental Disabilities, Washington, DC
- 2004 Keynote Speaker, National Accrediting Agency for Clinical Laboratory Sciences, Chicago, IL
- 2004 Keynote Speaker, Molecular Aspects of Infection and Inflammation Common Pathways, Rare Pediatric Diseases Conference, Bethesda, MD
- 2004 Speaker, Secretary's Advisory Committee on Genetics, Health, and Society, Bethesda, MD
- 2004 Plenary Speaker, Presidential Session, Annual Conference, American Public Health Association, Washington, DC
- 2005 Keynote Speaker, Annual Meeting, National Coalition for Health Professional Education in Genetics, Bethesda, MD
- 2005 Speaker, World Healthcare Summit, Washington, DC

- 2005 Speaker, Annual Meeting, Academy of Orthopaedic Surgeons, Washington, DC
- 2005 Keynote Speaker, CDC Senior Leadership Symposium, Atlanta, GA
- 2005 Grand Rounds Speaker, Academic Hospital Maastricht, Maastricht, the Netherlands
- 2005 Speaker, National Heart, Lung, and Blood Institute conference: "The Next Step: Population Studies in the '-Omic' Age," Bethesda, MD
- 2005 Speaker, Annual Conference, National Council of La Raza, Philadelphia, PA
- 2005 Keynote Speaker, Annual Institute and Conference, National Black Nurses Association, Chicago, IL
- 2005 Keynote Speaker, Annual Conference, the Genetic Alliance, Bethesda, MD
- 2005 Speaker, Congressional Briefing, Society for Women's Health Research, Washington, DC
- 2005 Keynote Speaker, "Global Health: A Bridge to the Future Conference," sponsored by Boston University and RAND, Boston, MA
- 2006 Panelist, Annual Meeting, American Clinical Laboratory Association, Washington, DC
- 2006 Speaker, Grand Rounds, Department of Medicine, University of Maryland School of Medicine, Baltimore, MD
- 2006 Panelist, "Genes in the Workplace: The Right Fit?" Conference, Washington, DC
- 2006 Keynote Speaker, March of Dimes Salk Symposium, San Diego, CA
- 2006 Keynote Speaker, 2006 Health Care Industry Study, Ft. McNair, Washington, DC
- 2006 Keynote Speaker, First Annual Research Retreat, University of Alabama-Birmingham Department of Genetics, Birmingham, AL
- 2006 Keynote Speaker, 2006 National Judges' Science School, Chicago, IL
- 2006 Keynote Speaker, International Society of Nurses in Genetics Annual Conference, New Orleans, LA
- 2006 Grand Rounds Speaker, Department of Pediatrics, Children's Hospital at Montefiore, New York, NY
- 2006 Speaker, Sarah Lawrence College, New York, NY
- 2007 Speaker, the Glenn M. Weaver Institute of Law and Psychiatry, University of Cincinnati College of Law, Cincinnati, OH
- 2007 Speaker, Massachusetts Medical Society Annual Education Program, Boston, MA
- 2007 Speaker, Healthcare Executives Leadership Network, Chicago, IL
- 2007 Speaker, National Heart, Lung, and Blood Institute Comprehensive Sickle Cell Centers Steering Committee Meeting, Washington, DC
- 2007 Speaker, National Commission on Certification of Physician Assistants, Board Meeting, Raleigh, NC

- 2008 Keynote Speaker, American Association for Intellectual and Developmental Disabilities Annual Meeting, Washington, DC
- 2008 Keynote Speaker, Population-Based Carrier Screening for Single Gene Disorders: Lessons Learned and New Opportunities, Bethesda, MD
- 2008 Keynote Speaker, 4th International Conference on Rare Diseases and Orphan Drugs, Washington DC
- 2008 Keynote Speaker, 14th HHT Foundation International Patient and Family Conference, Chicago IL
- 2008 Speaker, Board of Regents, National Library of Medicine, Bethesda, MD
- 2008 Speaker, Advisory Panel on Research, Association of American Medical Colleges, Washington, DC
- 2008 Keynote Speaker, American Health Information Management Association Annual Meeting, Seattle, WA
- 2008 Keynote Speaker, ASTAR National Judges' Science School, Bethesda, MD
- 2008 Speaker, NIH Director's Council of Public Representatives, Bethesda, MD
- 2008 Keynote Speaker, First Annual Symposium, University of Pennsylvania Center for Integration of Genetic and Healthcare Technologies, Philadelphia, PA
- 2008 Speaker, Annual Conference, American Society of Human Genetics, Philadelphia, PA
- 2008 Speaker, Department of Health and Human Services Healthcare Innovation Conference, San Francisco, CA
- 2008 Speaker, Department of Health and Human Services Healthcare Innovation Conference, Minneapolis, MN
- 2008 Speaker, Department of Health and Human Services Healthcare Innovation Conference, Boston, MA
- 2009 Speaker, Health Policy Lecture Series, Penn State College of Medicine, Hershey, PA
- 2009 Speaker, "The Promises and Pitfalls of Pharmacogenetics in Psychiatry" Symposium, Johns Hopkins University, Baltimore, MD
- 2009 Keynote Speaker, Scientific Symposium at the Dedication of Sanford Children's Hospital, Sioux Falls, SD
- 2009 Keynote Speaker, Plenary Session, Public Policy Council of the Society for Pediatric Research, American Pediatric Society, and Association of Medical School Pediatric Chairs, Baltimore, MD
- 2009 Keynote Speaker, American Clinical Laboratory Association Annual Meeting, Washington, DC
- 2009 Speaker, Vermont Summer Pediatric Seminar, Manchester, VT
- 2009 Speaker, Direct-To-Consumer Genetic Testing: A Cross-Academies Workshop, National

- Academy of Sciences, Washington, DC
- 2009 Keynote Speaker, Annual Meeting, National Coalition for Health Professional Education in Genetics, Bethesda, MD
- 2009 Speaker, National Summit on Personalized Health Care, Deer Valley, UT
- 2009 Discussant, Session on Frontiers in Cancer Genetic Testing: Addressing the Needs of Children, Adolescents, and Young Adults, American Society of Human Genetics, Honolulu, HI
- 2009 Speaker, Presidential Symposium, American Society of Human Genetics, Honolulu, HI
- 2009 Keynote Speaker, Annual Meeting, American College of Allergy, Asthma & Immunology, Miami, FL
- 2009 Speaker, Massachusetts General Hospital Breast Cancer Conference
- 2010 (Scheduled) Keynote Speaker, Annual Meeting of the American Pharmacists Association, Washington DC
- 2010 (Scheduled) Visiting Professor, Department of Pediatrics and Lecturer, Department of Human Genetics, University of Michigan, Ann Arbor, MI

### **OTHER PRESENTATIONS**:

1987-Present Over 500 other presentations on topics in pediatrics, genetics, and genomics and over a hundred media interviews regarding genetics, genomics, personalized medicine, etc.

#### **GRANTS AND CONTRACTS:**

1992

1985-1987	National Research Service Award, Department of Health and Human Services, \$51,000 (Trainee)
1987-1999	Annual Grants/Contracts for Genetics Services, from the Department of Health, State of Vermont, totaling approximately \$1,390,000 (PI)
1987-1990	Grants to the Pregnancy Risk Information Service from the Vermont Chapter of the March of Dimes Birth Defects Foundation totaling approximately \$7,500 (PI)
1987-1989	Family Health Evaluation Project, New England Regional Genetics Group, \$36,325 (Co-PI)
1989-1999	Annual Contracts for Newborn Screening Services, from the Department of Health, State of Vermont, totaling approximately \$550,000 (PI)
1992-1999	Annual subcontracts for Genetics Services from the Department of Health, State of New York, totaling approximately \$216,000 (PI)

Linkage studies in Hereditary Hemorrhagic Telangiectasia, National Institutes of

	Health - (Consultant)
1995-1996	"Familial Cancer Program," Lake Champlain Cancer Research Organization, \$250,000 (Co-PI)
1995-1997	The Vermont Human Genetics Initiative, Dean's office and multiple departments, University of Vermont College of Medicine - \$264,000 (PI)
1997	Vermont Pregnancy Risk Information Service Newsletter, Vermont and Northeastern New York Chapters, March of Dimes Birth Defects Foundation (Co-PI) \$6,000
1996-1999	The Genetics of Hereditary Hemorrhagic Telangiectasia, National Institutes of Health - (Consultant)
1998-1999	The Community Genetics and Ethics Project, National Institutes of Health (1 R25 HG01680-01) - \$579,245 (PI)

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Hoyme HE, Der Kaloustian VM, Hogg H, Entin MA, **Guttmacher AE**. Possible common pathogenetic mechanisms for Poland sequence and Adams-Oliver syndrome: an additional clinical observation. Amer J Med Genetics 1992;42:398-399.

Lea DH, Gardiner GB and **Guttmacher AE**. Preconceptional family health evaluation: a regional education program for family planning clients and health professionals. J Gen Counsel 1992; 1:251-258.

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**Guttmacher AE**, McKinnon WC, Upton MD. Hereditary hemorrhagic telangiectasia: a disorder in search of the genetics community. (Letter) Amer J Med Genetics 1994;52:252-253.

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McBride CM, **Guttmacher AE**. Commentary: Trailblazing a Research Agenda at the Interface of Pediatrics and Genomic Discovery—a Commentary on the Psychological Aspects of Genomics and Child Health. J Pediatr Psychol. 2009;34:662-4.

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DH, Buscarini E, Chesnutt MS, Cottin V, Ganguly A, Gossage JR, **Guttmacher AE**, Hyland RH, Kennedy SJ, Korzenik J, Mager JJ, Ozanne AP, Piccirillo JF, Picus D, Plauchu H, Porteous MEM, Pyeritz RE, Ross DA, Sabba C, Swanson K, Terry P, Wallace MC, Westermann CJJ, White RI, Young LH, Zarrabeitia R. International Guidelines for the Diagnosis and Management of Hereditary Hemorrhagic Telangiectasia J Med Genet. 2009; Published Online First: 23 June 2009.

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Collins FS, **Guttmacher AE**. The Human Genome Project and our future health. In Health & Health care 2010: The Reactions. The Institute of the Future for the Robert Wood Johnson Foundation. Princeton, NJ. January 2000; 17-18.

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#### Books –

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#### Book Chapters –

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