

GSPP Advisors

Biographies

Alliance for Aging Research

Daniel Perry – Executive Director

Daniel Perry is the Executive Director of the not-for-profit Alliance for Aging Research in Washington, D.C. Mr. Perry's organization is the nation's leading citizen advocacy organization for promoting a broad agenda of medical and behavioral research to improve the health and independence of older Americans.

Mr. Perry's background spans a wide range of health policy, governmental, political and journalistic experience. Mr. Perry held staff positions for more than a dozen years on Capitol Hill, including special assistant to the Majority Whip of the U.S. Senate. He was appointed by Health and Human Services Secretary Louis Sullivan during the first Bush Administration to the Federal Task Force on Aging Research. He was also named by President Clinton to the Advisory Board of the White House Conference on Aging. As part of the influential Jackson Hole Group on healthcare issues, Mr. Perry helped establish the groundwork for the Foundation for Accountability, or FACCT, and served as Chairman of the FACCT Board of Directors. Mr. Perry was selected to represent consumer interests on the first governing body of the American Medical Accreditation Program (AMAP), assessing credentials and performance of U.S. physicians.

Mr. Perry is the current President of the Coalition for the Advancement of Medical Research (CAMR), leading over 90 patient advocacy organizations, scientific and medical societies and leading research universities in the fight to advance stem cell research. He is also a Board member of the California Foundation for Stem Cell Research, a Director of the Institute on Aging at the University of the Pennsylvania and a member of the New York Academy of Sciences.

Mr. Perry is a frequent speaker on aging research and public policy topics before business, academic, and public sector audiences, and is widely published on these subjects. As a journalist he was the recipient of many awards and citations, including a nomination for the Pulitzer Prize.

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American Association of Family Practitioners

David Weismiller, ScM

David G. Weismiller is an Associate Professor of Family Medicine and Vice Chair Department of Family Medicine at The Brody School of Medicine at East Carolina University. He is a graduate of Jefferson Medical College of Thomas Jefferson University and completed a residency in family medicine at the University of Virginia Health Sciences Center where he served as Chief Resident. In addition, he completed a fellowship in maternal-child health and a Master of Science degree in epidemiology at Brown University School of Medicine.

A diplomate of the American Board of Family Medicine, Dr. Weismiller is a practicing clinician and provides full spectrum clinical care, including maternity care. His primary clinical and research focus is in Maternal Child Health. His funded research focuses on the epidemiology of perinatal depressive symptoms and tobacco use. He is an active lecturer nationally on family centered perinatal care and family planning and has been recognized by his current institution with the designation of *Master Educator*. He is the author of numerous abstracts, peer-reviewed articles, and book chapters.

A native of Washington DC, Dr. Weismiller is an avid musician and the father of three talented women – Hillary, Meredith, and Bronwyn.

American Civil Liberties Union

Barry Steinhardt

Barry Steinhardt served as Associate Director of the American Civil Liberties Union from 1992 until 2002, when he became its inaugural Director of the Program on Technology and Liberty. He has helped lead a variety of activities aimed at shedding light on relevant issues, combating flawed rules and legislation, and empowering individual activism. It was requests filed under the Freedom of Information Act, for example, that revealed the deficiencies of facial recognition systems being tested for law enforcement purposes. Court action sought to limit efforts under the Communications Assistance for Law Enforcement Act (CALEA) to build surveillance capabilities into America's communications infrastructure. In the wake of revelations that the airline jetBlue had turned vast amounts of passenger information over to the U.S. government, a Web form was developed to enable the public to automatically file requests under the Privacy Act to see what personal information the government had obtained.

Mr. Steinhardt has been a prominent advocate for privacy and other civil liberties in the face of technologically-oriented threats. In addition to testifying before the U.S. Congress, he has addressed audiences ranging from the National Conference of State Legislatures to the UNESCO Conference on Intellectual Property. As the latter suggests, his activism has not been confined to the U.S.

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He was a co-founder of the Global Internet Liberty Campaign-the world's first international coalition of non-governmental organizations (NGOs) concerned with the privacy and free speech rights of Internet users-and a member of the US delegation to the G-8 Government and Private Sector Tokyo Conference on Cyber Crime. His advocacy also extends to the media. His essays have appeared in such diverse publications as USA Today, CIO magazine, and the journal of the Davos World Economic Forum and he has appeared on a variety of news and talk shows.

American College of Medical Genetics

Michael S. Watson, PhD

Dr. Watson received his B.S from American University in Washington, D.C. and his M.S. in Medical Genetics and Ph.D. in Physiology and Biophysics from the University of Alabama at Birmingham. He is Executive Director of the American College of Medical Genetics and an Adjunct Professor of Pediatrics at Washington University in St. Louis where he was Director of Clinical and Molecular Cytogenetics from 1986 – 2000. He is certified by the American Board of Medical Genetics in Clinical Cytogenetics and PhD Medical Genetics.

Dr. Watson has a long standing interest in the translation of genetic information into health care use. He was a founder of the American College of Medical Genetics for which he has served as Vice President for Laboratory Affairs and has chaired its Test and Technology Transfer Committee, Economics Committee, Laboratory Practices Committee and Intellectual Property Committee. He co-chaired the NIH-ELSI/HHS Task Force on Genetics Testing from 1995 – 1997. Most recently, he was the project director for a MCHB/HRSA funded project to bring uniformity to newborn screening in the United States. He is currently the Director of the National Coordinating Center for Regional Genetics and Newborn Screening Collaboratives..

Dr. Watson has been the author of over 75 peer reviewed publications and book chapters.

American Medical Association

Lawrence T. O'Connor, MD

Dr. O'Connor received his B.S. from Saint Joseph's College and his Ph.D. from the University of Illinois at Urbana-Champaign.

He is currently overseeing scientific and public health policy activities in the field of genetics and molecular medicine at the American Medical Association. He has written several reports for the AMA Council on Scientific Affairs on subjects relating to stem cell research, genetic testing, and newborn screening. Dr. O'Connor also maintains the AMA Genetics and Molecular Medicine Web site

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(www.ama-assn.org/go/genetics). Prior to joining the AMA, he worked as a research scientist at the pharmaceutical company Wyeth. He has also conducted research at the University of Wisconsin-Madison and at the University of California-Irvine. He has published more than 15 research articles and is co-inventor on 4 drug-related patents.

Dr. O'Connor serves as AMA representative on the Board of Directors for the National Coalition for Health Professional Education in Genetics (NCHPEG) and is actively involved in NCHPEG's Family History Working Group. He is author of an AMA educational monograph entitled *Family Medical History in Disease Prevention* and is collaborating with the software developer Progeny to develop an online pedigree-drawing tool.

Over the last year, Dr. O'Connor has been working with the AMA's Health Disparities Working Group to develop educational materials for physicians on the latest advances in the field of pharmacogenomics and personalized medicine.

American Society of Human Genetics

Joann Boughman, PhD

Dr. Boughman is the chief executive officer of the American Society of Human Genetics (ASHG), the primary professional organization (~8,000 members) of researchers, physicians, laboratory scientists and genetic counselors in North America, who are actively engaged in discovery, teaching, and health care applications in human genetics.

Dr. Boughman received her Bachelor's and Ph.D degrees from Indiana University. She was a faculty of the Medical College of Virginia, and then the University of Maryland, Baltimore where she was first an Associate Professor and then Full Professor in the School of Medicine, and a Research Professor of Periodontics in the Dental School. She remains an Adjunct Professor of Obstetrics/Gynecology and Pediatrics at the University of Maryland, School of Medicine. Dr. Boughman served as Vice President of the University of Maryland, Baltimore and Dean of the Graduate School for a decade.

She is a Board certified Medical Geneticist, elected to the Board of Directors and then Secretary and Vice President of the American Board of Medical Genetics, and a Founding Fellow of the American College of Medical Genetics. Dr. Boughman served on the Secretary's Advisory Committee on Genetic Testing (SACGT), chairing the Education Workgroup for that Committee. She chairs the Molecular and Clinical Genetic Devices Panel of the FDA, and is a Commissioner of Higher Education for the State of Maryland.

Boughman has performed research in population genetics and epidemiology of blindness and hearing impairments, congenital heart malformations, periodontal

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disease, and is the author of many publications. She has presented at many national and international scientific meetings, and has been a faculty participant in judicial workshops sponsored by the Einstein Institute for Science, Health and the Courts.

Dr. Boughman and her husband are proud owners of two Newfoundland dogs (Dreyfuss and Lilleth), who thoroughly enjoy their work as psychiatric therapy dogs.

Association of Genetic Technologists Peggy Stupca, MS, CLSp (CG), CLSup

Peggy Stupca has been active in the field of cytogenetics since 1972. She is currently the Program Director for a cytogenetic technologist training program. She has been a member of the Association of Genetic Technologists AGT since it was founded in 1975; served on the Board of Directors as annual meeting chair from 1990 – 1992; and served on AGT Council of Representatives (COR) as the representative to the National Accrediting Agency for Clinical Laboratory Services (NAACLS) from 1996 – 2000. She served on Board of Directors 0 NAACLS from 1996 – 2000. Ms. Stupca currently serves on the AGT COR as representative to the National Credentialing Agency for Laboratory Personnel, and is Vice President of the NCA Board of Directors.

Association of Maternal and Child Health Programs Meg Booth, MPH

Meg Booth has served as a Policy Analyst for children with special health care needs and early childhood issues at the Association of Maternal and Child Health Programs (AMCHP) since May of 2002. Prior to her time at AMCHP she worked to educate policy makers on Medicaid and SCHIP issues as a Policy Associate at the Alliance for Health Reform and as a private consultant at the Center on Budget and Policy Priorities. In addition, Ms. Booth also worked in North Carolina on child-care research, local public health department assessments, and an evaluation of North Carolina's strategies to enroll children into public health care coverage. Ms. Booth's experience also includes nearly three years with the Family Services Bureau at the Iowa Department of Public Health developing the state Title V Block Grant application and outreach strategies for enrolling Iowa's children into Medicaid and SCHIP coverage. Ms. Booth holds a bachelor of arts in Community Health Education with a Women's Studies minor from the University of Northern Iowa. She also obtained a Masters in Public Health from the Department of Maternal and Child Health at the University of North Carolina at Chapel Hill.

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Blue Cross Blue Shield Association of America Inger Sapphire-Bernstein, MHSA

Inger Sapphire-Bernstein is Assistant Director, Physician and External Relations, in the Office of Clinical Affairs at the Blue Cross and Blue Shield Association (BCBSA).

At BCBSA, Ms. Sapphire-Bernstein facilitates the formulation of clinically-oriented policy for the National Council of Physician Executives and the Office of Clinical Affairs. She supports development of legislative and regulatory policy and industry standards impacting quality and medical management, technology assessment, and physician relations. She is also principal staff within OCA for: initiatives to promote the affordability of pharmaceuticals, genomics, and genetic testing, HIPAA, and performance measurement and reporting. Ms. Sapphire-Bernstein has been with BCBSA for 17 years and previous roles included development of: Blue Quality Centers for Transplant, the Demonstration Project on Breast Cancer Treatment, and the Pediatric Cancer Network. She has also worked closely with a number of national clinical organizations, including: the American Academy of Pediatrics, American College of Radiology, American Chiropractic Association, and the American College of Medical Genetics on appropriateness of care, benefit design, coding, and issues.

Prior to joining BCBSA in 1987, Ms. Sapphire-Bernstein was Director of Planning for an HMO and for the University of Illinois Hospital. Earlier positions included Director of Long-Term Care Policy for the Massachusetts Medical Assistance Program. Ms. Sapphire-Bernstein received an AB from Radcliffe College, Harvard University, and an MHSA from the University of Michigan School of Public Health.

Child Health Corporation of America Don Black – President

As President of Child Health Corporation of America (CHCA), Don has seen this business organization of pediatric hospitals grow from a handful of institutions to the nation's largest business alliance of children's hospitals. Don leads CHCA in strategic planning, pediatric-focused investing, member services, membership growth and new business development.

Don has worked in the health care industry for over 20 years. He began his career at Creighton Omaha Regional Health Care Corporation in 1976. From Omaha, Don accepted a position at Excelsior Springs City Hospital where he served as Administrator. In 1979 he moved to Kansas City where he held a variety of positions with Health Midwest. His last assignment at Health Midwest was Vice President of Marketing and Development. In this position, Don was responsible for planning, directing and controlling marketing and sales functions,

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developing corporate sales plans and providing marketing consultation to the management of system hospitals. Don also became an investment banker, specializing in health care, at Piper, Jaffray & Hopwood, Inc.

Don is involved in a number of professional organizations, including the American College of Health Care Executives, the Society of Health Care Planning and Marketing and The Young Presidents Organization. He currently serves on several outside corporate boards and charity organizations. He holds a B.A. from the University of Kansas and a Masters in Hospital and Health Care Administration from the University of Minnesota.

The Council of State Governments

Trudi Matthews, MA

Trudi is the Associate Director for Health Policy at The Council of State Governments' headquarters office located in Lexington, Kentucky. The Council of State Governments (CSG), organized in 1933, is the nation's premier organization in forecasting policy trends for state and territorial leaders. CSG's membership encompasses all three branches of government, including governors, lieutenant governors and other constitutional officers, state legislators, and executive branch agency officials and their staff.

In her position with CSG, Trudi is responsible for staffing its national Health Task Force and Emerging Health Trends Subcommittee, as well as writing, researching and planning meetings on a wide variety of health policy issues, including Medicaid, the uninsured, prescription drugs, public health, chronic illness and disease management, health literacy, health professional shortages, bioterrorism and health system preparedness among others.

Prior to joining CSG, Trudi worked as Coordinator for the Board of Directors for Administrators in Medicine, a state government association for medical board executives in all 50 states. Prior to that, she served as an Executive Officer at the Iowa Board of Medical Examiners where she was responsible for administering the Board's confidential program for impaired physicians. Trudi also worked as an Information Analyst at the Iowa Board responsible for policy research, preparing regulations, legislation tracking as well as physician licensure and disciplinary issues. She has also taught political science courses for Iowa State University and the Des Moines Area Community College.

Trudi received her BA and MA in political science from Iowa State University. A native of Kansas City, she currently lives outside Lexington, Kentucky with her husband and four children.

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Genetic Alliance

Sharon Terry, MA –President and CEO

Sharon is President and CEO of the Genetic Alliance, a coalition of over 600 disease specific advocacy organizations working to increase capacity in those groups and to leverage the voices of millions of individuals and families affected by genetic conditions. She is the founding Executive Director of PXE International, an advocacy group for the genetic condition pseudoxanthoma elasticum (PXE). Following the diagnosis of their two children with PXE in 1994, Sharon, a former college chaplain, and her husband, Patrick, founded and built a dynamic organization that fosters ethical research and policies and provides support and information to members and to the public.

She is at the forefront of a consumer participation in genetics research, services and policy and serves as a member of many of the major governmental advisory committees on medical research, including the National Institute of Arthritis Musculoskeletal and Skin Diseases Council and the Food and Drug Administration Cellular, Tissue and Gene Therapies Advisory Committee. She served as an Ethical Legal and Social Implications Research Advisor of NHGRI/NIH, and currently is liaison to the National Advisory Council for Human Genome Research. She is a member of the board of directors of the Biotechnology Institute and on the advisory board of the Johns Hopkins Genetics and Public Policy Center funded by the Pew Charitable Trusts. She was recently elected to the boards of the Personalized Medicine Coalition, DNA Direct and the Center for Information and Study on Clinical Research Participation. She is the chair of the Coalition for Genetic Fairness, composed of advocates, providers and industry working to educate congress about genetic discrimination so that they will pass legislation to prohibit it. Along with the other co-inventors of the gene associated with PXE (ABCC6), she holds the patent for the invention. She co-directs a 19-lab research consortium and manages 52 offices worldwide for PXE International.

Ms. Terry founded the Genetic Alliance Biobank and serves as president of its board. The Biobank is a cooperative biological samples and data repository that allows lay advocacy and community organizations to bank and manage samples and data, thereby accelerating research both within and across disease by providing access to fully protected, linked samples in a centralized collection.

Sharon feels strongly that consumers, working together and partnering with professionals and industry, can generate the energy and mechanisms necessary to realize the promise of biomedical research. Her work with the Genetic Alliance over the past few years has particularly focused on genetic literacy, research protections, biosample repositories, technology translation, genetic nondiscrimination, accessible services and youth issues. Sharon is committed to

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facilitating technical assistance to advocacy organizations, so that each organization benefits from the wisdom of the other.

Sharon lives with Patrick and their two children in Maryland.

Health Research & Educational Trust Frances S. Margolin, MA

Frances S. Margolin is Senior Director, Operations and Applied Research, at the Health Research and Educational Trust (HRET), the research affiliate of the American Hospital Association (AHA). In that role she is responsible for internal operations of the organization, including finances and standard support functions and is liaison to other units within the AHA. She supports the President of HRET in strategic development and organizational management and serves as part of the senior management team. She is also responsible for development of an agenda focusing on community health and hospital-community relationships. This agenda includes research, leadership development, education, and an individual membership group, the Association for Community Health Improvement.

Currently she is co-Principal Investigator on a four-year Cooperative Agreement with the Centers for Disease Control and Prevention designed to help hospitals in the effort to completely eliminate perinatal HIV transmission. She is also heading up a new research team across units of the AHA studying governance of nonprofit hospitals and health care systems.

Previously she was Director of Community Health Programs and led the second phase of the Community Care Network Demonstration Program. This national demonstration supported the work of eight public-private partnerships across the country, all of which focused on improving the health of the community. In that role, she conceptualized and led the creation of a series of practical tools, the capstone of which was a comprehensive guide to creating and sustaining community health partnerships. She joined HRET in the spring of 1997 as CCN Research Manager, implementing the CCN evaluation project under the direction of its principal investigators.

Prior to coming to HRET, Ms. Margolin worked as assistant director in charge of research and training at two social science research centers at the National Opinion Research Center and the University of Chicago. The research centers focused on demography and on demography and economics of aging. Her own research has broadly looked at unintentional limitations to access to health care, and she has substantial prior experience in textbook and professional publishing, much of it focusing on special education, speech and language pathology, neuropsychology, and achievement testing.

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Ms. Margolin has an M.A. in Public Policy, with certification in Health Administration and Policy, from the Harris School at the University of Chicago, and a B.A. from Smith College.

Healthwise

Donald Kemper, MPH

Donald W. Kemper is Chairman and CEO of Healthwise, Incorporated. Since its founding in 1975, Kemper has directed the Healthwise mission “to help people make better health decisions”. Every day more than 100,000 people turn to Healthwise information for help in managing their health care problems.

Kemper co-authored the Healthwise Handbook used by millions of American families to manage common illnesses. He inspired development of the Healthwise® Knowledgebase which is integrated in the Web sites of nine of the top ten health plans, WebMD, MSN, and hundreds of hospitals.

Kemper was the founding chairman of Hi-Ethics, creating the ethical standards now followed by URAC’s Health Web Site Accreditation Program.

Acclaimed for his visionary leadership in consumer health, Kemper’s efforts are currently focused on Information Therapy—the prescription of information to the patient as a part of their process of care. He anticipates information prescriptions becoming part of every clinic visit.

IBM

Brett Davis

Brett Davis is a Global Solutions Executive in IBM’s Information Based Medicine business unit, part of IBM Healthcare and Life Sciences. In this role, Mr. Davis is involved in helping shape the marketing and solutions strategy for the unit’s clinical genomics, high performance computing, biobanking and translational research solutions and strategy. In addition to his role at IBM, he is on the Board of Directors of the Personalized Medicine Coalition and has been an invited speaker/panelist at industry meetings on information technology’s transformative role in the health sciences. Prior to joining IBM, Mr. Davis led business development and marketing efforts at Genstruct, Inc., a Cambridge, MA based biotech. Previously he served as Senior Product Manager and Director of Marketing for Viaken Systems, Inc., where he helped develop and market bioinformatics and knowledge management solutions for pharmaceutical research. He has also served in commercial development roles at Dow Chemical and Air Products & Chemicals. Mr. Davis is a graduate of The Pennsylvania State University where he completed the accelerated Science BS/MBA Program, and graduated as the Eberly College of Science Student Marshall.

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International Society of Nursing Genetics

Judith Lewis, PhD, RNC, FAAN

Dr. Judith Lewis is Professor in the Maternal Child Nursing department, where is also Director of Information Technology for the School of Nursing. A native of Massachusetts, she received an AB in English and American literature from Brandeis University and a BS in nursing from Boston University. She traveled to California for her Master's degree, which is from the University of California at San Francisco. Her master's program included preparation as a women's health nurse practitioner. Her PhD is in health policy from the Heller School at Brandeis University. She has completed a post master's certificate program in online teaching, the University of Cincinnati Children's Hospital Genetics Institute for Nursing, and the NIH/NINR Summer Genetics Institute.

Dr. Lewis is active in several professional nursing organizations. She holds memberships in numerous organizations, including the American Nurses Association, Sigma Theta Tau International, the National League for Nursing, the Southern Nursing Research Society, and the International Society of Nurses in Genetics. She has received the Distinguished Professional Service Award from the Association of Women's Health, Obstetric, and Neonatal Nurses, has been elected to the National Academy of Practice in Nursing, and is a Fellow of the American Academy of Nursing. She has received the Mary Ann Garrigan Award from the Theta-at-Large chapter of Sigma Theta Tau International, the 2001 Founders Award for Service from the International Society of Nurses in Genetics, and the 2001 Nicholas Andrew Cummings Award from the National Academies of Practice. In 1999, Dr. Lewis was appointed by Secretary of Health and Human Services Donna Shalala to the Secretary's advisory Committee on Genetic Testing, where she served for 3 years as one of 13 voting members. She currently is immediate past president of the International Society of Nurses in Genetics.

MEDCO Health Solutions, Inc.

Duke University

Patricia Deverka, MD, MS

Patricia Deverka recently joined Duke's Institute for Genome Science and Policy as a Fellow in the Center for Genome Ethics, Law and Policy. She was previously employed as a health services researcher in the pharmaceutical and managed care industries, focusing primarily on the clinical and economic outcomes of pharmaceutical treatments and drug benefit plan designs. Most recently Dr. Deverka was Vice President of Scientific Affairs at Medco Health, where she developed strategies to help pharmacy benefit managers and payers evaluate advances in pharmacogenomics and plan for responsible diffusion of personalized prescribing into the marketplace. Her current research interests

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include empiric evaluation of the ethical and policy dimensions of introducing new genomic-based technologies (tests and drugs) into clinical practice. Dr. Deverka earned her medical degree from the University of Pittsburgh School of Medicine, a master's degree in Preventive Medicine from the University of Maryland and a master's degree in bioethics from the University of Pennsylvania.

National Coalition for Health Professional Education in Genetics

Joe McInerney, MS, CGC

Joseph D. McInerney, executive director of the National Coalition for Health Professional Education in Genetics (NCHPEG), holds an MS in genetic counseling from SUNY Stony Brook. He joined the coalition on September 1, 2000. Prior to that, McInerney was director of the Foundation for Genetic Education and Counseling and spent 22 years on the staff of the Biological Sciences Curriculum Study (BSCS), where he was director from 1985 to 1999. He was a member of the information and education committee of the American Society of Human Genetics from 1988-1999 and is a member of the editorial boards of the *Quarterly Review of Biology* and *Community Genetics*.

McInerney was principal investigator on a NCHPEG project to develop an interactive CD-ROM on psychiatric genetics, for free distribution to all members of the National Society of Genetic Counselors, of which he is a charter member. He now is principal investigator on NCHPEG projects to develop an interactive CD-ROM on genetics and common chronic disease and on race, genetics, and health care. He directed development of the BSCS programs *Basic Genetics: A Human Approach* (2nd and 3rd editions); *Advances in Genetic Technology; Evolution: Inquiries into Biology and Earth Science*; and *Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy*, which was distributed free of charge to 50,000 high school biology teachers in the United States. He also directed development of three other instructional modules on the Human Genome Project, all of which have been distributed nationwide for free. He was principal investigator on projects to develop five interactive CD-ROMS (genetics and cancer; human genetic variation; emerging and re-emerging infectious diseases; systematics and taxonomy; and developmental biology) and co-principal investigator for development of an instructional module on the RNA world, for undergraduate biology.

McInerney is a former president of the 8,000-member National Association of Biology Teachers (U.S.) and in 1989 was awarded lifetime membership in that organization. In 1996, he was elected a Fellow in the American Association for the Advancement of Science. He was a member of the Human Genome Project's working group on ethical, legal, and social implications (ELSI) of human genome research and recently concluded a four-year tenure on the ELSI study

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section of the National Human Genome Research Institute (NHGRI). McInerney was also a member of the National Academy of Sciences' *ad hoc* committee on evolution and creationism, which produced two publications on the evolution/creation issue. He has published more than 90 articles, reviews, and chapters in the scientific and science-education literature.

National Conference of State Legislatures

Alissa Johnson, MA

Alissa Johnson is a Senior Policy Specialist with the Genetic Technologies Project at the National Conference of State Legislatures (NCSL), where she provides state legislatures and their staff with objective, comprehensive, and scholarly information to facilitate the drafting of sound genetics legislation. Her responsibilities include tracking and analysis of state genetics laws and legislation, providing technical assistance to state legislators and staff on genetics policy issues and responding to requests from state and federal policymakers, the media, and others. Ms. Johnson has published works on numerous genetics policy issues, including newborn screening, privacy, discrimination, and reproductive genetics.

National Newborn Screening & Genetics Resource Center

Celia Kaye, MD, PhD

Dr. Kaye received her B.S. and M.D. from Wayne State University in Detroit, Michigan and her Ph.D. from Northwestern University in Chicago, Illinois. She is a Professor of Pediatrics at The University of Texas Health Science Center at San Antonio in San Antonio, Texas, and served as the Chairman of the Department of Pediatrics from 1997 - 2002. She is currently the Vice Dean for the School of Medicine.

Dr. Kaye has a long standing commitment to medical education, inborn errors of metabolism, and newborn screening. She has served on numerous federal and state committees and task forces and is currently a member of the American Academy of Pediatrics Committee on Genetics and the Executive Committee of the American College of Medical Genetics Special Interest Group on Public Health. She is also a senior advisor for the National Newborn Screening and Genetics Resource Center and serves on the Steering Committee of the National Council on Folic Acid. She has served on the Texas Genetics Council; the Uniform Panel Workgroup of the American College of Medical Genetics; the Task Force for Newborn Screening of the Texas Department of Health; the Scientific Advisory Committee on Birth Defects in Texas, the Chair for the Clinical Genetics Advisory Committee, Bureau of Women and Children; the Medical Advisory Board, Chromosome 18 Registry and Research Society; Medical Advisory Board of the Hemifacial Microsomia Family Support Network; and the Medical Advisory Committee of the Texas Sickle Cell Association.

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Dr. Kaye has been the author of numerous peer reviewed publications, chapters, manuals and education media, and has been the principal investigator of over 25 federally and privately funded projects in genetics and health services research.

National Society of Genetic Counselors Daragh Conrad, MS

Daragh Conrad earned her BS in Molecular, Cellular, and Developmental Biology from the University of New Hampshire. She was awarded a Masters degree in Human Genetics at Sarah Lawrence College in Bronxville, NY in 1995. She was certified by the American Board of Genetic Counseling in 1996. She has served as a certified genetic counselor in the Department of Pediatrics, Section on Medical Genetics at the Wake Forest University Baptist Medical Center in Winston-Salem, North Carolina since entering the field. Her practice focuses primarily on prenatal, pediatric, and adult genetic counseling and coordination of a maternal serum screening program.

Ms. Conrad has presented abstracts at several national meetings including the National Society of Genetic Counselors Annual Education Conference and the American College of Medical Genetics Conference. She has been published in the Journal of Genetic Counseling, American Journal of Medical Genetics, and Clinical Genetics.

Other professional activities including educating medical students and residents in a wide range of specialties about genetics and genetic counseling. Ms. Conrad supervises genetic counseling students from the University of North Carolina at Greensboro Genetic Counseling Training Program. Ms. Conrad also serves on the external advisory board and currently is chairing the clinical training committee for the self study assessment for the Genetic Counseling Training Program at the University of North Carolina at Greensboro where she has an adjunct faculty appointment.

As an active member of the National Society of Genetic Counselors (NSGC), she has been appointed co-chair of the Health Care Delivery Models Task Force, charged with assessing and defining existing service delivery models and exploring potential new models of service delivery. She has also been an active participant in the NSGC's professional education, and she will co-chair the 25th Annual Education Conference in Nashville, TN in November, 2006.

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SG2

Leslie Wainwright, PhD

Leslie leads content development at Sg2. In this capacity, Leslie oversees the development of clinically-focused deliverables for both Edge and Strategic Services clients. She is also responsible for Sg2's molecular medicine and laboratory diagnostics portfolio which leverages her background in biotechnology and pharmaceuticals.

Prior to joining Sg2, she was a consultant with Technomic International's BioScience Group. While at Technomic she worked with pharmaceutical industry clients on competitive analysis, strategic planning, and pipeline evaluation projects. These engagements provided pharmaceutical clients with suggestions and actions regarding future technology investments and strategic professional alliances. Earlier in her career, Leslie has served as the Associate Director of the Kellogg Center for Biotechnology at Northwestern University. At Northwestern, Leslie managed, developed, and taught biotechnology-specific curricula for the Center's Master of Science in Biotechnology program, a program which focused on the synergy of business and science. She also contributed to programs designed to promote biotechnology entrepreneurship within the Chicago and Illinois communities.

Leslie is a noted speaker on genomics, molecular medicine and the impact that advances in these areas will have on the delivery of healthcare. She frequently addresses management teams, boards, and professional organizations on emerging technology and how to respond to the changing health care landscape.

Leslie has a scientific background in the field of infectious microbiology. She completed her Ph.D. in the Department of Microbiology at Northwestern University. She has completed post-doctoral research training at the Center for Vaccine Development at the University of Maryland. Her work has focused on several different aspects of bacterial pathogenesis with her independent research projects being funded by both the National Institutes of Health and the Cystic Fibrosis Foundation. She received a B.A. degree in biology from DePauw University.

Superior Consultant Company, Inc.

Jeffery Bauer, PhD, Senior Vice President

Dr. Bauer is a nationally recognized health futurist and medical economist. He is Senior Vice President of Superior Consultant/ACS Healthcare Solutions (Dearborn, MI), a leading provider of outsourcing, information technology, and management consulting services to the health care industry. In his numerous publications and presentations, he forecasts the future of health care and

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describes practical, creative approaches to improving the healthcare delivery system.

Dr. Bauer has published more than 135 articles, books, Web pages, and videos on health care delivery. He speaks frequently to national audiences about key trends in health care, medical science, technology, reimbursement, information systems, public policy, and creative problem solving. Dr. Bauer is quoted often in the national press and writes regularly for periodicals that cover the business of health care. As a consultant, he assists hospitals and other provider organizations with leadership education, strategic planning and visioning, technology assessment, service line development, and clinical transformation management.

His latest book is *Telemedicine and the Reinvention of Health Care: The Seventh Revolution in Medicine* (McGraw-Hill, 1999), co-authored with Marc Ringel, MD. His two previous books are *Not What the Doctor Ordered* (McGraw-Hill, 1998) and *Statistical Analysis for Health Care Decision-Makers: Understanding and Evaluating Critical Information in a Competitive Market* (McGraw Hill, 1996). He is currently writing a book on the future of health care information and publishing a series of Web articles on key trends in selected clinical services (e.g., diagnostic imaging, orthopedics, home health, pharmaceuticals, molecular and genetic medicine, cardiology).

Dr. Bauer was a full-time teacher and administrator at the University of Colorado Health Sciences Center in Denver (1973-1984). He held full-time academic appointments as Associate Professor in the Schools of Medicine and Dentistry and administrative appointment as Assistant Chancellor for Planning and Program Development. He served concurrently as Health Policy Advisor to Colorado Governor Richard D. Lamm (1980-1984). He also worked as a visiting clinical professor in the Administrative Medicine Program at the Medical School of the University of Wisconsin-Madison (1992-1997), where he taught physician executives how to evaluate research reports and other published studies. Additionally, Dr. Bauer was a Senior Fellow at the Center for the New West in Denver (1992-2001). His previous consulting firm, The Bauer Group, Inc., specialized in consumer-focused strategic planning for developing clinical affiliation agreements and multi-hospital networks (1984-1992).

He received his PhD in Economics from the University of Colorado-Boulder. He graduated from Colorado College in Colorado Springs with a BA in Economics and completed a certificate in political studies at the University of Paris (France). During his academic career, he was a Boettcher Scholar, a Ford Foundation Independent Scholar, a Fulbright Scholar (Switzerland), and a Kellogg Foundation National Fellow.

Biographies

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UCHSC Center for Bioethics and Humanities

Mark Yarborough, PhD

Director of the Center for Bioethics and Humanities; and Associate Professor, Department of Preventative Medicine and Biometrics; University of Colorado at Denver and Health Sciences Center.

As Director of the Center for Bioethics and Humanities, Dr. Yarborough has provided leadership to: 1) Create and implement an ethics and humanities curriculum for the School of Medicine; 2) Foster inter-professional teamwork required in tomorrow's health care settings; 3) Implement regular ethics meetings in Intensive Care Units at University Hospital and The Children's Hospital; 4) Offer lectures and case-based ethics presentations to faculty and staff of clinical departments at the University of Colorado Hospital, The Children's Hospital, and the Veterans Administration Medical Center; and 5) Advance knowledge in the field of bioethics. Dr. Yarborough's scholarly publications that address ethical issues in many areas of health care, such as artificial feeding at the end of life, genetic counseling, human subjects research, insurance underwriting, and the role of profit in medicine, have appeared in both medical and bioethics journals. He is co-author of *Medicine and Money: A Study of the Role of Beneficence in Health Care Cost Containment* and former Chair of the Department of Philosophy at the University of Colorado at Denver.

UGA

Edward J. Larson, JD, PhD

Edward J. Larson is the Russell Professor of History and Talmadge Professor of Law at the University of Georgia and recipient of the 1998 Pulitzer Prize in History. Before accepting a teaching position at Georgia in 1987, he served as Associate Counsel for the U.S. House of Representatives Committee on Education and Labor (1983-89) and as an attorney with a major Seattle law firm (1979-83).

The author or co-author of nine books and over eighty published articles, Larson writes about issues of science, medicine and law from an historical perspective. His books include *Evolution: The Remarkable History of a Scientific Theory* (2004), *Evolution's Workshop: God and Science in the Galapagos Islands* (2001), *Sex, Race, and Science: Eugenics in the Deep South* (1995), *Trial and Error: The American Controversy Over Creation and Evolution* (1985, 1989, and 2002 expanded editions) and the Pulitzer Prize winning *Summer for the Gods: The Scopes Trial and America's Continuing Debate Over Science and Religion* (1997). His articles have appeared in such varied journals as *Nature*, *Atlantic Monthly*, *Science*, *Scientific American*, *The Nation*, *Michigan Law Review*, and *Virginia Law Review*. He is the co-author or co-editor of six additional books, including his most recent book, *The Constitutional Convention: A Narrative*

Biographies

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History from the Notes of James Madison (2005). Larson held the Fulbright Program's John Adams Chair in American Studies for 2001; he received the AAAS's Sarton Award in 2000; participated in NSF's Antarctic Writers and Artists program in 2003-04; and received an honorary doctorate degree from Ohio State University in 2004.

Larson lectures and speaks on history, law, science, and bio-ethics for academic, professional and public audiences. He has delivered endowed or funded addresses at dozens of colleges or universities, including California Institute of Technology, the University of Minnesota, and Vanderbilt University, and was commencement speaker at two universities. He has given papers at scores of academic conferences throughout the world, and legal and medical education talks to professional legal, judicial and medical groups across the country. He is interviewed frequently for broadcast and print media, including multiple appearances on PBS, the History Channel, C-SPAN and NPR. His course on the history of evolution theory is available from The Teaching Company.

Born in central Ohio, Larson attended Mansfield, Ohio, public schools. He earned a B.A. from Williams College, a law degree from Harvard, and a Ph.D. in the History of Science from the University of Wisconsin-Madison. The recipient of several teaching awards, he currently holds a joint appointment in the history department and law school at the University of Georgia, where he teaches the history of science to undergraduates and health, science and technology law to law students. He has also taught in Austria, China, France, New Zealand and the Netherlands. He is married to a pediatrician, Lucy Larson. They have two children, Sarah and Luke. Together, they enjoy travel, hiking, bicycling, and working on their 180-year-old house in Athens, Georgia.