

## HRSA/MCHB Representatives

### **Claude Earl Fox, M.D., M.P.H.**

*Administrator, Health Resources and Services Administration*

Local, State and Federal service have distinguished Dr. Fox's career as a public health care advocate. He came to HRSA from the HHS office of Disease Prevention and Health Promotion, where he was deputy assistant secretary for health from November 1995 to March 1997. He previously served as an HHS regional health administrator. He has also enjoyed a distinguished public health career at the State and local levels, including tenure as the State health officer in Alabama from 1986 to 1992 and deputy State health officer in Mississippi, 1983 to 1986. He was involved in the development of the Children's Health Insurance Program [CHIP]. Born on November 8, 1946, Dr. Fox was reared in Charleston, Mississippi. He received his MD degree from the University of Mississippi School of Medicine in 1972. His first clinical experience was a local health department in Charleston, a recipient of HRSA funds. He earned a master of public health degree at the University of North Carolina and served pediatric residencies at Johns Hopkins Hospital in Baltimore and at the University of Mississippi Medical Center in Jackson. Dr. Fox is licensed to practice medicine in Maryland, is board certified in preventive medicine and public health and board qualified in pediatrics.

### **Merle McPherson, M.D., M.P.H.**

*Director, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau*

Dr. McPherson received her medical degree from the University of Saskatchewan in Canada in 1959 and holds the Masters of Public Health degree from Johns Hopkins School of Public Health. She is certified by the American Board of Preventive Medicine and has worked in pediatric clinical settings at the local, State and international levels. She has had administrative responsibilities for the Title V Crippled Children's program, and for primary pediatric care in the District of Columbia, and for the Title V Maternal and Child Health Program and for Family Health Services in the State of Hawaii. Dr. McPherson has held various positions in Maternal and Child Health at the Federal level since 1976 and is the recipient of numerous honors and awards.

**Michele Lloyd-Puryear, M.D., PH.D.**

*Chief, Genetic Services Branch, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau*

Dr. Lloyd-Puryear received her medical degree from Georgetown University School of Medicine in 1983 and received her doctorate in Genetics in 1978 from the George Washington University-National Institutes of Health program. She is a board-certified pediatrician and has worked in pediatric clinics at the local and international levels. She has held academic appointments and is still actively involved in teaching both medical students and pediatric residents in community health sites as an Assistant Clinical Professor at Georgetown University School of Medicine. She has administrative responsibilities for the Genetic Services Program in the Health Resources and Services Administration and Maternal and Child Health Bureau. Dr. Lloyd-Puryear has held various positions in the Health Resources and Services Administration since 1991 and is the recipient of numerous honors and awards.

**Marie Mann, M.D., M.P.H.**

*Deputy Chief of the Genetic Services Branch  
Maternal and Child Health Bureau*

Dr. Mann received her medical degree from Tulane University School of Medicine in 1982 and holds a Master of Public Health degree from the University of North Carolina in Chapel Hill. A fellow of the American Academy of Pediatrics, Dr. Mann received her pediatrics residency training at Charity Hospital New Orleans, Tulane University Medical Center, and Duke University Medical Center. Prior to joining the Federal government, she practiced pediatrics in the community. She is the mother of three daughters.

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## Support Staff

(Those who have coordinated, assisted, and facilitated these invitational meetings.)

### **Kay Johnson, M.P.H., ED.M.**

*Research associate professor*

*Dartmouth College*

*President, Johnson Group Consulting, Inc.*

Ms. Johnson is currently working on a history of the past twenty years of developments in child health policy and politics. Ms. Johnson is co-principal investigator (with Alice Sardell of Queens College) of the project “Children’s Health Policy: Actors, Issues and Process” supported by a Robert Wood Johnson Foundation Health Investigator Award. The Johnson Group provides consultant services, including: analysis of emerging questions, facilitation to further consensus developments, and assessment of national and State program and policy needs and trends—particularly in the area of maternal and child health. Current projects include work for the Alpha Center, American Academy of Pediatrics, Commonwealth Fund, Genetic Services Branch of the Division of Children with Special Health Care Needs – MCHB-HRSA, George Washington University Center for Health Services Research and Policy, National Immunization Program-CDC, and National Perinatal Association. Ms. Johnson has 15 years of experience in health policy through direct lobbying, consultation to state and local policy makers, and nationwide studies of program implementation. Her expertise encompasses a wide range of maternal and child health issues, including immunization, perinatal care, infant mortality, genetics, oral health, and services for children with disabilities. She has worked at the George Washington University Center for Health Policy Research, the March of Dimes Birth Defects Foundation, and the Children’s Defense Fund.

### **John Reiss, PH.D.**

*Director, Policy and Program Affairs*

*Institute for Child Health Policy*

*Associate Professor of Pediatrics, University of Florida*

In his role as Director of the MCHB-funded cooperative agreement Center for Policy and Partnerships, Dr. Reiss facilitates the State Title V CSHCN Program Targeted Technical Assistance Workgroup; the Federal Healthy and Ready to Work InterAgency Work Group; and the Healthy and Ready to Work Network. The mission of the Center and these national work groups is to facilitate collaborative action among public and private sector organizations at the Federal, regional, State and local levels to improve the organization, financing and delivery of health care service systems for children and adolescents with chronic health and disabling conditions. The focus of the Federal Healthy and Ready to Work InterAgency Work Group and the Healthy and Ready to Work Network is on enhancing policies and programs in support of the transition of adolescents and young adults with chronic health and disabling conditions to work. Barriers to successful transition that are being addressed through these work groups include inadequate access to health insurance, lack of interagency transition planning, and lack of career development that involves both job skills and management of chronic illness. Dr. Reiss received his Ph.D. from the University of Florida in Counseling Psychology and his Master of Psychology from Wesleyan University, Middletown, Connecticut. Dr. Reiss joined the Institute in 1986.

**Patti Hackett, M.E.D.**

*Senior Youth Policy Associate  
Institute for Child Health Policy*

Ms. Hackett provides technical assistance to Maternal and Child Health funded Projects, state Title V Programs and family organizations and serves as liaison to Federal agencies on strategies to promote and implement Healthy and Ready to Work initiatives on behalf of children and youth with disabilities. As a former educator and family-child advocate, Ms. Hackett brings a twenty-year commitment to inclusive education, leadership in implementing legislative initiatives and creative problem solving. As a parent of an adult with significant special needs, she has served as a consumer representative on national advisory boards and presented at numerous national policy meetings. Ms. Hackett earned her Master of Education in Learning and Behavior Disabilities from Xavier University in Cincinnati, Ohio, and a Bachelor of Science in Elementary Education from Worcester State College in Massachusetts. Ms. Hackett joined the Institute in 1993.

**Garrett Hall, M.A.M.C.**

*Communications Associate  
Institute for Child Health Policy*

Mr. Hall brings journalism and public relations/marketing experience to the Institute and serves as a vital liaison to the public and MCH community by creating and disseminating print and electronic information. He also assists in coordinating and facilitating national meetings and preparing post-meeting products. He is completing his Master of Arts in Mass Communication at the University of Florida and received a Bachelor of Arts in English with an emphasis in creative writing from Florida State University in 1993. Mr. Hall joined the Institute in 1997.

**Syraj Syed, M.A.M.C.**

*Technology & Training Associate  
Institute for Child Health Policy*

As the Web Master and Listserv manager for the MCH Netlink-Plus project, Mr. Syed understands the importance of supporting, integrating, and updating Web technology as well as providing the technology in a user-friendly, service-oriented manner. Mr. Syed designs, develops, and maintains web sites and listservs for the MCH community and provides technological support to Institute staff and Institute grant initiatives. Mr. Syed earned a Master of Arts in Mass Communication from the University of Florida College of Journalism and Communications and a Bachelor of Arts in Philosophy and English from the School of Liberal Arts and Sciences at Tufts University. Mr. Syed joined the Institute in 1999.

## Meeting One Speakers

### **Ed McCabe, M.D., PH.D.**

*Professor and Executive Chair*

*UCLA Department of Pediatrics*

*Physician-in-Chief*

*Mattel Children's Hospital at UCLA*

Dr. McCabe received his medical degree (1974) and a Ph.D. in Pharmacology (1972) from the University of Southern California. He is certified by the American Board of Pediatrics and the American Board of Medical Genetics (Clinical Genetics and Biochemical Genetics). He served on the faculty at the University of Colorado Health Science Center and Baylor College of Medicine before accepting his current position at UCLA in 1994. For the American Academy of Pediatrics, he chaired the Committee on Genetics, and co-founded the Section on Genetics and Birth Defects. He served as President of the American Board of Medical Genetics. He is currently a member of the NICHD Council, President-Elect of the American College of Medical Genetics, and Chair of the Secretary's Advisory Committee on Genetic Testing.

### **Joann Lindenmayer, D.V.M., M.P.H.**

*Chronic disease epidemiologist*

*Rhode Island Department of Health*

*Director, M.P.H. Program in the Department of Community Health*

*Assistant Professor*

*Brown University School of Medicine*

Dr. Lindenmayer is an active member of the Council of State and Territorial Epidemiologists, an ASTHO affiliate. In that capacity, she currently serves as lead genetics consultant and co-authored a national survey on the role of State public health agencies in genetics and disease prevention. Dr. Lindenmayer received her veterinary medical degree from Tufts University School of Medicine in 1985, and her Masters of Public Health degree from the Harvard School of Public Health in 1988. She was an Epidemic Intelligence Field Service Officer of the CDC and more recently completed a four year contract with the State-based Epidemiology for Public Health Program Support [STEPPS] program of the National Center for Chronic Disease Prevention and Health Promotion.

**Kathleen Rand Reed, B.S.**

*President, GeoGeneSys tm (Geographic Genetic Systems)*

Dr. Reed is president of Geographic Genetic Systems or GeoGeneSys, a research and media/marketing firm specializing in sociocultural and ethnic training for health and medical professionals in geodemographic, and transcultural relations. Dr. Reed is a practicing applied biocultural anthropologist. At San Francisco State University, she designed one of the university's few triple majors to receive her degree—"Culture and Media in Biomedical Geomarkets" from the departments of Biology, Behavioral and Social Sciences and Broadcast/Electronic Communication. Dr. Reed has served as a grant proposal reviewer for DHHS, with regard to the ethnocultural aspects of transplantation and genetics as well as a panelist for the National Research Council/National Academy of Sciences' "Workshop on Race and Ethnic Classification." She has trained more than 150 coordinators for the North American Transplant Coordinator Organization [NATCO] on ethnocultural issues in transplantation, and produced several health-care and transplant radio programs including a three-part Culture in Health Series. Her honors include an Commission appointment by the late San Francisco Mayor, George C. Moscone, a recent California Joint Assembly and Senate tribute, and a Congressional Record tribute by Congresswoman, Anna G. Eshoo.

**Mary Davidson, M.S.W.**

*Executive Director*

*Alliance of Genetic Support Groups*

Ms. Davidson currently represents consumers and families on the Secretary's Advisory Committee on Genetic Testing [SACGT]. She has a Masters in social work and came to the Alliance with a rich background that mixed skills and experiences in clinical social work, organizational development and health advocacy. She brings a consumer, as well as a professional, perspective to her work at the Alliance because of family incidence of genetic conditions. Her professional and personal experiences are broad and diversified and include community organization in the Peace Corps and several other overseas work assignments in Germany, Vietnam, and Japan. She devoted more than twenty years to practice as an individual, group, and family psychotherapist, specializing in the treatment of psychiatric problems secondary to medical conditions, chronic pain, family conditions and cultural dislocation.

**Donna Gore Olsen**

*Executive Director, Indiana Parent Information Network, Inc. Indianapolis, Indiana*

Donna Gore Olsen is the parent of three children. Her two youngest children (a twenty-year-old son and an eighteen-year-old daughter) have cystic fibrosis. Donna is the co-founder and executive director of the Indiana Parent Information Network, Inc. [IPIN], a state wide organization of parents and professionals who provide information, support and education to parents of children with special needs and to professionals who work with them. IPIN has been the recipient of numerous grants to assist with the development and implementation of special projects regarding family-centered, community based systems of care for children with special health care needs in the areas of child care, health care financing, and parent education. Ms. Olson is a charter member of Family Voices and is a State coordinator for Family Voices Indiana. In the area of genetic services, she has been a member of the Great Lakes Area Genetics Group [GLARGG] since 1988 serving on the Steering Committee and the Consumer Issues Subcommittee. She also has served as a Board Member of the Alliance of Genetic Support Groups (1991-95) and is the author of an article for the Journal of Obstetric, Gynecologic, and Neonatal Nursing (1994), "Parental Adjustment to a Child with Genetic Disease: One Parent's Reflections."

## Meeting Two Speakers

### **Bob Fineman, M.D., PH.D.**

*Medical Consultant*

*Washington State Department of Health*

Dr. Fineman has been working in the field of genetics for almost thirty years as a clinician, laboratorian, researcher, teacher, administrator, and mentor. He has considerable experience at the local, state, regional and national levels in public health genetics assessment, policy development and assurance including financial, ethical, legal and social issues. He is particularly interested in cultural awareness, cultural competency and access to services for traditionally under-served populations. Dr. Fineman also has worked as a primary care physician, member of the Washington State Department of Health/Department of Social and Health Services Human Research Review Board, and as a grant writer and reviewer. He has published and/or presented more than 100 manuscripts in peer-reviewed journals and at national and international meetings. He also has served as a consultant to many public and private agencies, organizations, and institutions throughout the United States.

### **Brad Therrell, PH.D.**

*Director, National Newborn Screening and Genetic Resource Center*

*University of Texas Health Science Center at San Antonio*

Dr. Therrell received his doctorate in Inorganic Chemistry from the Florida State University of Tallahassee, Florida in 1971 and an Honorary Doctor of Medicine from Kunming Medical College in China in 1997. He is certified by the Board of Bioanalysis as a High Complexity Laboratory Director and served 28 years with the Texas Department of Health. Dr. Therrell has numerous publications primarily in the area of newborn screening and has served as an expert for the International Atomic Energy Agency in a number of developing countries. He has been active both nationally and internationally in organizing newborn screening symposia and currently serves as Past President of the International Society for Neonatal Screening.

**Peter Simon, M.D., M.P.H.**

*Assistant Medical Director  
Rhode Island Department of Health*

Dr. Simon serves as the Deputy Medical Director, Division of Family Health with programmatic responsibilities ranging across the spectrum of core public health functions for the traditional maternal and child health populations. Dr. Simon is a graduate of Cornell University and the State University of New York, Upstate Medical School in Syracuse. He received his MPH from Johns Hopkins University in 1976. He is certified by the American Board of Preventive Medicine and the American Board of Pediatrics. After working as a private practitioner in Pawtucket, RI, he joined the RI Department of Health as a Medical Epidemiologist in 1984 after having served for six years as a Pediatric Consultant for the State’s Immunization and Childhood Lead Poisoning Prevention Programs. He has had multiple roles with the Title V Program at the State, regional and national level as well as serving the American Academy of Pediatrics at the State and national levels. He presently chairs the Board of Directors of the Public Education Fund in Providence, RI and is the past Chairman of the Board of the Ocean State Free-Net and Providence Babe Ruth Baseball. Dr. Simon has been a Red Sox fan since the Dodgers left Flatbush.

**Robb Linkins, PH.D.**

*Chief, Systems Development Branch NIP, CDC*

Dr. Linkins is currently Chief, Systems Development Branch, National Immunization Program at the Centers for Disease Control and Prevention in Atlanta, Georgia. The principle mission of Dr. Linkins’ branch is the facilitation of the development of local and State-based immunization registries in the United States. Prior to his current position, Dr. Linkins was responsible for developing immunization information systems in more than 40 countries throughout the world. Dr. Linkins received his Masters of Public Health degree from the University of California, Berkeley, and his Ph.D. in Epidemiology from John Hopkins School of Public Health.

**Martin Wolfson**

*Vice President, Neometrics*

Mr. Wolfson helped found Neometrics in 1978. He is responsible for the advance, design, and development of database systems for newborn screening. He serves on the NCCLS subcommittee for newborn screening and has assisted in the development of the standard for blood collection. He has spent many years with many committees on newborn screening both internationally and domestically, doing grand rounds in St. Croix, Uruguay, and Japan. He received degrees from City College of New York in physics and has worked on many aerospace projects including the lunar module.



## Meeting Three Speakers

### **Betsy Shenkman, PH.D.**

*Director, Health Services Research and Evaluation*

*Institute for Child Health Policy*

*Associate Professor of Pediatrics, University of Florida*

Dr. Shenkman is the Principal Investigator on several research projects designed to assess the quality of care that children receive within managed care and the factors influencing that care. Her funded projects include: Contractual Arrangements with Physicians: Implications for Pediatric Health Care; The Healthy Kids Program Evaluation; Quality of Care for Children With Special Health Care Needs in Managed Care; Identifying and Tracking the Quality of Care for Children with Special Health Care Needs in Managed Care; Evaluating Florida KidCare; and Access to Care for Low-Income Adolescents. Dr. Shenkman has published articles and reports on children's health care in managed care settings. In addition, she has presented several papers on the organization and financing of children's health care at the Association for Health Services Research and the American Public Health Association national meetings.

### **Andrew Nelson, M.P.H.**

*Executive Director*

*HealthPartners Research Foundation*

Mr. Nelson received his Masters of Public Health degree in Public Health Administration from the University of Minnesota. As Executive Director of the HealthPartners Research Foundation for the past nine years, he provides leadership at this public-domain, scientific, health research center with more than 85 staff and 350 active research projects. HealthPartners is an integrated health delivery system that includes a group and staff model HMO servicing more than 800 thousand people in Minnesota. Prior to the HealthPartners Research Foundation position, he was executive director for eight years at the Day Community Program at the University of Minnesota, a day-treatment program for emotionally and behaviorally disturbed adolescents. He worked at the University of Minnesota Health Sciences Division as a project officer for five years. He is a founding member and current Chair of the Board of Directors for the HMO Research Network—13 research organizations with external funding of nearly one hundred million dollars.

**Holly Grason, M.A.**

*Director of the Women’s and Children’s Health Policy Center  
Associate Scientist, Department of Population and Family Health Sciences  
Johns Hopkins School of Public Health*

Ms. Grason’s graduate training is in the field of child development. She has more than seven years of state-level experience in the administration of public health programs for MCH populations and worked for more than five years at the national level conducting research and policy analysis and policy development related to the functions, organization, and financing of state level services for women and children, including the Title V MCH Services Block Grant and the Medicaid Program. As Director of the WCHPC, Ms. Grason is responsible for development and oversight of multidisciplinary faculty research and product development in the application of research to the practice of public MCH program implementation. Ms. Grason’s key contributions to maternal and child health have centered on development of frameworks for describing and analyzing issues related to the roles, organization, and functions of public programs serving women and children.

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