Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action

Committee

Marie C. McCormick

Chair

Marie Claire McCormick, M.D., Sc.D., is a Sumner and Esther Feldberg Professor of Maternal and Child Health (Emerita), Professor of Pediatrics, and a pediatrician with a second doctorate in health services research. Her research has focused on the effectiveness of perinatal and neonatal health services, and the effect they have on the health of women and children. Dr. McCormick's research has also given particular attention to the outcomes of premature infants. She has been a senior investigator on the evaluations of national demonstration programs such as the Robert Wood Johnson Foundation National Perinatal Regionalization Program. She was also an investigator for the federal Healthy Start Program. In addition, she has provided substantial input to the design and conduct of Infant Health and Development Project, which is the largest, multisite randomized trial of early childhood educational intervention. Dr. McCormick received her M.D. and Sc.D. from Johns Hopkins University and her B.A. from Emmanuel College. Dr. McCormick is a member of the National Academy of Medicine and a recipient of the David Rall Medal.

Gilda Barabino

Member

Gilda Barabino, Ph.D., is the Dean and Berg Professor at The Grove School of Engineering at The City College of New York (CCNY). She has appointments in Biomedical Engineering, Chemical Engineering and the Sophie Davis School of Biomedical Education/CUNY School of Medicine. Previously, Dr. Barabino served as the Associate Chair for Graduate Studies and Professor in the Wallace H. Coulter Department of Biomedical Engineering and the Vice Provost for Academic Diversity at Georgia Tech and Emory University. Dr. Barabino's laboratory focuses on vascular and orthopedic tissue engineering research. She also works to find novel therapeutic strategies that will improve the health of those who suffer from sickle cell disease and related complications. Dr. Barabino received her B.S. degree in Chemistry from Xavier University of Louisiana and her Ph.D. in Chemical Engineering from Rice University.

Mary C. Beach

Member

Mary Catherine Beach, M.D., M.P.H., is a professor of medicine at the Johns Hopkins University School of Medicine. She holds a joint appointment in health, behavior and society at the Johns Hopkins Bloomberg School of Public Health. Dr. Beach's scholarship about respect and relationships in healthcare encompasses both empirical and conceptual dimensions. Dr. Beach is currently conducting research on the theoretical foundations of respect and the impact of physician attitudes and patient-physician communication on patients in the primary care setting, in the treatment of HIV and substance abuse and in the treatment of sickle cell disease. Dr. Beach is on the editorial board for Patient Education and Counseling and on the Advisory Board for Communication in Medicine.

Lori E. Crosby

Member

Lori E. Crosby, Psy.D, is a Professor of Pediatrics and a clinical psychologist. She is Co-Director of Innovations in Community Research and Co-Directs the Cincinnati Clinical Translational Science Award's (CTSA) Community Engagement Core. Dr. Crosby's research focuses on community engagement, self-management, quality improvement, sickle cell disease, health disparities, and patient centered outcomes and has been funded by the National Institutes of Health, Agency for Healthcare Research and Quality, and the Patient Centered Outcomes Research Institute. She is an elected Fellow of the American Psychological Association and a faculty member in the Department of Pediatrics at the University of Cincinnati (UC) College of Medicine, the Division of Behavioral Medicine at Cincinnati Children's Hospital Medical Center, and the Department of Hematology/Oncology at UC Health (adjunct). Dr. Crosby previously served as a member of a National, Heart, Lung and Blood Institute Workgroup that developed 2020 Healthy People objectives for individuals affected by sickle cell disease and an American Psychological Association on Advancing Practice. Dr. Crosby received her Psy.D. from Wright State University and completed her pediatric residency/internship at Cincinnati Children's Hospital Medical Center.

Amy Dawson

Member

Amy Dawson, M.D, M.P.H is Associate Director and Medical Director at the Fort Wayne Medical Education Program, a family medicine residency program dually-accredited by both the Accreditation Council for Graduate Medical Education (ACGME) and the American Osteopathic Association (AOA). After earning her M.D. degree from The Ohio State University, Dr. Dawson trained in family medicine at the Fort Wayne Medical Education Program. Following her training she spent 3 years in private practice at Brooklyn Medical Associates, followed by four and half years as Medical Director of Matthew 25 Health and Dental, and almost four years practicing in Quito, Ecuador. In July of 2012, she moved back to Indiana and joined the faculty of the Fort Wayne Medical Education Program as medical director of the Family Medicine Clinic, training new family medicine doctors to provide great healthcare now and in the future.

Darius Lakdawalla

Member

Darius Lakdawalla, Ph.D., is the Quintiles Chair in Pharmaceutical Development and Regulatory Innovation at the University of Southern California (USC), where he sits on the faculties of the School of Pharmacy and the Sol Price School of Public Policy. He also serves as the Director of Research at the Leonard D. Schaffer Center for Health Policy and Economics at USC, one of the nation’s premier health policy research centers. Dr. Lakdawalla is currently a Research Associate at the National Bureau of Economic Research and serves as an Associate Editor for the Review of Economics and Statistics, the Journal of Health Economics and the American Journal of Health Economics. He is considered an expert in the field of health policy and economics, with his research focusing primarily on the economics of risks to health, the value and determinants of medical innovation, the economics of health insurance markets, and the industrial organization of healthcare markets. Dr. Lakdawalla received his Ph.D. in economics from the University of Chicago and his B.A. in mathematics and philosophy from Amherst College.

Bernard Lopez

Member

Bernard Lopez, M.D., M.S. is the Executive Vice Chair in Department of Emergency Medicine, a Team Emergency Physician for the Philadelphia Flyers, the Associate Dean of Diversity and Community Engagement at Sidney Kimmel Medical College, and the Associate Provost of Diversity and Inclusion at Thomas Jefferson University. Dr. Lopez’s research interests include clinical and basic science aspects of acute vaso-occlusive sickle cell crisis in adult emergency department patients and unconscious bias and its role in health disparities. Dr. Lopez received his M.D. from the Sidney Kimmel (formerly Jefferson) Medical College.

Jonathan D. Moreno

Member

Jonathan D. Moreno, Ph.D., is a David and Lyn Silfen University Professor of Ethics at the University of Pennsylvania in the Department of Medical Ethics and Health Policy. He is a Senior Fellow at the Center for American Progress in Washington, D.C. and the author of several books on ethics. Dr. Moreno received his Ph.D. from Washington University and his B.A. from Hofstra University. Dr. Moreno is a member of the National Academy of Medicine.

Enrico Novelli

Member

Dr. Novelli is an Associate Professor of Medicine at the University of Pittsburgh and an expert in sickle cell disease. He received his fellowship training in Hematology/Oncology at the University of Pittsburgh Medical Center (UPMC). Dr. Novelli has served as Director of the UPMC Adult Sickle Cell Program since 2007 and as the Chief of the Section of Benign Hematology at UPMC since 2018. Dr. Novelli's research focus is on vascular dysfunction and biomarker development in sickle cell disease, with a special interest in the area of cognitive dysfunction, for which he has received uninterrupted National Institutes of Health funding. He has numerous publications in sickle cell disease and has served as a scientific reviewer for many journals, the National Institutes of Health and the American Heart Association. He is a member of several American Society of Hematology committees. Dr. Novelli has been actively interested in advancing hematological care in low income countries and have led the first two hemophilia symposia in Tanzania under the auspices of a partnership between the World Federation of Hemophilia, the Tanzanian Hemophilia Chapter and the Hemophilia Center of Western Pennsylvania (HCWP). In 2015, he has been elected as co-chair of the American Society of Hematology African Newborn Screening and Early Intervention Consortium in sickle cell disease. This ambitious initiative aims to bring together institutions in sub-Saharan Africa to introduce standardized practices for screening and early intervention therapies (such as penicillin prophylaxis and vaccinations) with the goal of decreasing childhood mortality rates for sickle cell disease.

Andrew Orr-Skirvin

Member

J. Andrew Orr-Skirvin, Pharm.D., BCOP, is an Associate Clinical Professor at Northeastern University in the Department of Pharmacy and Health Systems Sciences. He specializes in hematology/oncology pharmacy practice. Dr. Skirvin's research is in supportive care which includes pain management, nausea & vomiting, neutropenic fever, long-term complication, and growth factor support. He received his Doctor of Pharmacy degree from the University of Texas at Austin and The University of Texas Health Science Center at San Antonio. He received his Bachelor of Science in Pharmacy, Oregon State University.

Ifeyinwa Osunkwo

Member

Ifeyinwa (Ify) Osunkwo, M.D., MPH, is the Director for the Sickle Cell Disease Enterprise at Atrium Health's Levine Cancer Institute serving approximately 1400 adults and 400 children living with sickle cell disease. She is a Clinical Associate Professor of Medicine at the University of North Carolina at Chapel Hill and a lifespan hematologist who specialized in health services outcomes in sickle cell disease with a specific focus on transition from pediatrics to adult care chronic pain, health literacy and patient engagement. She is also an implementation science researcher with a specific focus on sickle cell disease. Dr. Osunkwo has over 25 years of experience in clinical management and population health for sickle cell disease as it relates to chronic disease management, quality improvement and program development. She is a PI on the Education and Mentoring to Bring Access to CarE (EMBRACE) Network - a regional collaborative focused on increasing access to care for individuals living with sickle cell disease in the southeast USA and leads the Sickle Cell Trevor Thompson Transition Project (SST3P-UP) a multicenter study to comparative the effectiveness of a structured education based transition program with or without peer mentoring on transition outcomes among emerging adults with sickle cell disease. Dr. Osunkwo serves on the board of the Sickle Cell Adult Providers Network (SCAPN) and on several committees for the American Society of Hematology (ASH) namely the ASH Communications Committee, The ASH Cardiopulmonary and Renal Guidelines subcommittee, and on the editorial board for The Hematologist and Hematology News. Dr. Osunkwo received her M.D. from the University of Nigeria, and her M.P.H. from Johns Hopkins Bloomberg School of Public Health. She completed he clinical training at University of Medicine and Dentistry of New Jersey (Pediatric Residency) and Columbia University (Fellowship in Pediatric Hematology/Oncology and Bone Marrow Transplant).

Susan Paulukonis

Member

Susan Paulukonis, M.P.H., M.A. is the Program Director of the California Rare Disease Surveillance Program at Tracking California, a partnership between the Public Health Institute and the California Department of Public Health. Her expertise is in using population surveillance methodologies to gather information on those affected by rare, non-reportable diseases, determining the incidence and prevalence of such disorders and their outcomes and impact. This work also identifies and highlights those resources that may are needed to improve quality of life for affected populations. The primary focus of her work is sickle cell disease, but the program has also conducted population surveillance in amyotrophic lateral sclerosis, Parkinson's disease, and human health impacts of exposure to cyanotoxins. Susan was responsible for management of California's Registry and Surveillance System for Hemoglobinopathies (RuSH) and Public Health, Epidemiology, Research and Surveillance in Hemoglobinopathies (PHRESH) programs prior to her direction of the state's Sickle Cell Data Collection Program. Susan Paulukonis received her M.P.H. from the University of California, Berkeley, and her M.A. and B.A. from San Francisco State University.

Charmaine Royal

Member

Charmaine Royal, Ph.D., M.S., is Associate Professor of African & African American Studies, Biology, Global Health, and Family Medicine & Community Health at Duke University. She also has appointments in the Duke Initiative for Science & Society, the Kenan Institute for Ethics, and the Social Science Research Institute where she directs the Center on Genomics, Race, Identity, Difference and the Center for Truth, Racial Healing & Transformation. Dr. Royal's research and scholarship focus on scientific, clinical, ethical, social, and policy implications of genetic and genomic research globally, particularly issues at the intersection of genetics and constructs of race, ethnicity, ancestry, and other descent-related identities. She leads and is involved in a variety of domestic and international projects on sickle cell disease and trait. She received her Ph.D. in human genetics and M.S. in genetic counseling from Howard University, and completed postgraduate training in bioethics and ELSI (ethical, legal, and social implications) research at the National Human Genome Research Institute of the National Institutes of Health.

Kim Smith-Whitley

Member

Kim Smith-Whitley, M.D., is the Director of the Comprehensive Sickle Cell Center, Clinical Director of the Division of Hematology, and Professor of Pediatrics at the Children's Hospital of Philadelphia. She holds the Elias Schwartz, M.D., Endowed Chair in Hematology. Her research focus is on sickle cell disease-related complications particularly infections and pulmonary issues as well as improving long-term therapies and the transition process from pediatric- to adult-focused care. Through multiple projects and advocacy efforts she hopes to increase access to high quality care and foster the development of new therapeutics including curative therapies for children and adults with sickle cell disease. She is the initiator of two programs at Children's Hospital of Philadelphia: a short-stay Hematology Acute Care Unit and The Blue Tie Tag program to recruit blood donors for pediatric transfusions. Dr. Smith-Whitley received her M.D. from George Washington University School of Medicine then completed residency training at Children's National Hospital and pediatric hematology-oncology fellowship at Children's Hospital of Philadelphia.