Sickle Cell Disease in Social Security Disability Evaluations

Committee

Paul A. Volberding

Chair

Paul A. Volberding, MD, (Chair) is Professor of Medicine Emeritus at the University of California San Francisco (UCSF), the former director of the AIDS Research Institute, and co-director of the UCSF-GIVI Center for AIDS Research. Trained in medical oncology, he became involved in the early AIDS epidemic in San Francisco and has experience in clinical and translational research in antiviral therapeutics. Dr. Volberding is a Member of the National Academy of Medicine, a Fellow of the American Association for the Advancement of Science, a Master of the American College of Physicians, and a Fellow of the Infectious Diseases Society of America. He received his medical degree from the University of Minnesota and completed his residency at the University of Utah in internal medicine and his fellowship in medical oncology at UCSF. He is editor-in-chief of JAIDS: Journal of Acquired Immune Deficiency Syndromes and Current HIV/AIDS Reports and serves on data safety monitoring boards for the National Institutes of Health (NIH), Gilead Sciences, and Merk focused on drugs for HIV, COVID, TB, and other infectious diseases. Dr. Volberding currently serves on the National Academies of Sciences, Engineering, and Medicine’s Report Review Committee and the Standing Committee of Medical and Vocational Experts for the Social Security Administration’s Disability Programs and has chaired numerous National Academies’ committees, including several for the Social Security Administration, most recently the Committee on the Long-Term Health Effects Stemming from COVID-19 and Implications for the Social Security Administration.

Marilyn S. Baffoe-Bonnie

Member

Marilyn S. Baffoe-Bonnie, PhD, is a Postdoctoral Fellow in the Department of History and Sociology of Science at the University of Pennsylvania. She employs mixed methods to examine ethical and social dimensions of biomedical innovation through the lenses of medical sociology, science and technology studies, and bioethics. Her current research focuses on the use of gene therapy to treat sickle cell disease, with particular attention to health equity and the lived experiences of patients. Through this work, she seeks to inform ethical practices and improve outcomes in the integration of emerging biotechnologies. Her award-winning research has been published in Genetics in Medicine Open, Bioethics, and Social Science & Medicine. Dr. Baffoe-Bonnie serves on the NYU Pediatric Gene Therapy and Medical Ethics Working Group and the Red Blood Cell Antibody Exchange (RBCAX) Patient Engagement Subcommittee, which is associated with the federal Advisory Committee on Blood and Tissue Safety and Availability. Dr. Baffoe-Bonnie earned her PhD in Sociology from Rutgers University. She completed a Predoctoral Fellowship in Bioethics and Health Disparities at the National Institutes of Health Clinical Center Department of Bioethics and the National Human Genome Research Institute Health Disparities Unit in the Social and Behavioral Research Branch. She also holds a Master of Bioethics from the University of Pennsylvania and a Bachelor of Science in Psychology with minors in Health Studies and Peace, Justice, and Human Rights from Haverford College.

Cecelia L. Calhoun

Member

Cecelia L. Calhoun, MD, MPHS, MBA, is an Assistant Professor of Medicine (Hematology) and Pediatrics (Hematology-Oncology) at the Yale University School of Medicine. She also serves as the Medical Director of the Adult Sickle Cell Disease Program and Associate Chief of Operations at Yale Cancer Center and Smilow Cancer Hospital. Dr. Calhoun employs mixed methods to address the educational and healthcare challenges that are critical to the longevity of adolescents with sickle cell disease, a population disproportionately affected by health and healthcare disparities. She has dedicated her career to designing and implementing evidence-based interventions that support the successful transition from pediatric to adult care for individuals with sickle cell disease. Her work has been supported by the DeLuca Foundation for Innovation in Hematology, the National Institutes of Health, and the American Society of Hematology (ASH), where she co-directs the Sickle Cell Disease Centers Workshops and, as of 2025, serves on the ASH Committee on Government Affairs. She previously held consultancies with Bluebird Bio, Sanius Health, and CVS Caremark. She earned her MD from Wayne State University in her hometown of Detroit, MI, and completed her residency and fellowship training at Michigan State University and Washington University in St. Louis. She obtained her MBA from Yale University as a member of the inaugural cohort of the Pozen Commonwealth Fund Fellowship in Health Equity Leadership.

Jeffrey Glassberg

Member

Jeffrey Glassberg, MD, MA, is a Tenured Professor of Emergency Medicine and Hematology and Medical Oncology at the Icahn School of Medicine at Mount Sinai. After beginning his career in Emergency Medicine, Dr. Glassberg sought a career in research and clinical care of people with sickle cell disease (SCD). Following his fellowship, he assumed responsibility for SCD ambulatory care and inpatient consults. Since his arrival in 2010, Dr. Glassberg has built the Mount Sinai Center for Sickle Cell Disease into one of largest SCD centers in the country. Dr. Glassberg's research spans the translational spectrum from mechanistic studies to develop novel gene-editing cures and understand immune activation in SCD, ranging to qualitative and large database research. He has funding from several NIH grants including, most recently, a $12.3 million award where ten sites will follow more than 1000 patients to determine which combinations of new sickle cell drugs work best. Dr Glassberg currently serves on the Data Safety Monitoring Board for the drug etavopivat and previously served on advisory boards for Novartis and CSL Behring and participated in ROCHE's phase II-III studies of crovalimab. He has received numerous awards for his research, clinical care, and community engagement. Dr. Glassberg is a leader in promoting stakeholder engagement and evidence-based strategies for the management of Sickle Cell Disease, including co-authoring ASH Guidelines for SCD and working with the Centers for Medicare & Medicaid Services to develop quality metrics for SCD care. He has lectured internationally to hematologists and emergency providers on the topics ranging from mechanism-driven therapies to compassionate care and evidence-based algorithms for management of SCD.

Coretta M. Jenerette

Member

Coretta Jenerette, PhD, is the Thelma Shobe Endowed Chair, Professor, and Senior Health Equity Scholar at the University of California, San Francisco School of Nursing. Shortly after entering the nursing profession 30 years ago, Dr. Jenerette was exposed to the plight of adults with sickle cell disease (SCD) and quickly learned that the same rules for pain management did not apply to this population. She found that much of the inequity in care for individuals with SCD is due to social and structural determinants of health, implicit and explicit bias, lack of knowledge, myths about Black people, and racism. Her internationally recognized program of research focuses on improving self-care management and health outcomes for individuals with SCD and other minoritized, underrepresented populations. She is a servant leader and social justice advocate. She previously served on the Advisory Board of Sick Cells, an organization committed to educating the sickle cell community on policy and incorporating the sickle cell voice in legislation. Dr. Jenerette completed certificates in Diversity and Inclusion from Cornell University and Multicultural Mentoring from the University of Florida and is a Fellow of the American Academy of Nursing and the Academy of Nursing Education. She received a PhD and MSN from the University of South Carolina and her BSN from Clemson University. She also completed post-doctoral fellowships at Yale University and The University of North Carolina at Chapel Hill.

Ashley M. Jenkins

Member

Ashley Jenkins, MD, MS, is Assistant Professor of Medicine and Pediatrics at the University of Rochester Medical Center where she works as a combined internal medicine and pediatrics (Med-Peds) hospitalist taking care of hospitalized children and adults. She is also a health services researcher with a special interest in improving equitable hospital care delivery for adolescents and adults with chronic conditions of childhood like sickle cell disease. Dr. Jenkins has federal funding to adapt and study the effectiveness of individualized care plans for inpatient sickle cell care, a tool that has been effective at improving sickle cell care in the emergency department setting. She is a member and has committee roles in the American Society of Hematology, Society of Hospital Medicine, and National Alliance of Sickle Cell Centers. Dr. Jenkins is a graduate of Brown University (BA) and Eastern Virginia Medical School (MD). She completed a combined internal medicine and pediatrics (Med-Peds) residency training, chief residency, and a three-year combined pediatric and medicine hospital medicine fellowship at Cincinnati Children’s Hospital and University of Cincinnati Medical Centers. She was also a National Research Service Award fellow at Cincinnati Children's Hospital Medical Center. She received her Master of Science in Clinical and Translational Research through the University of Cincinnati in 2020.

Shirley A. Johnson

Member

Shirley A. Johnson, LSW, is a licensed social worker with more than 25 years of experience in areas of mental health, child welfare, and individuals with disabilities, and 15 years of experience in advocacy and care for patients with sickle cell disease (SCD). Currently, she is the Senior Research Program Manager in charge of managing the Virginia Commonwealth University (VCU) Adult Sickle Cell Medical Home, where her focus is on improving care, quality of life, and safety of patient care, while reducing utilization and cost to the healthcare system by using a team approach and Multidisciplinary Adult Care and Instrumental Support methods. Although her recent career is in project management, training, and development, Ms. Johnson led the charge in a foundation-funded transition program at VCU for patients with SCD aged 15 to 21. She has co-authored several peer-reviewed publications, including “Development of a framework to describe functions and practice of community health workers,” published in the Journal of Continuing Health Education Professionals. Currently, Ms. Johnson also serves as a co-facilitator for the annual SCCAPE (Sickle Cell Care Coordination for Achieving Patient Empowerment) conference, which is a national training conference for professionals working with SCD. She is a faculty member of the ASH Sickle Cell Disease Centers Workshop and serves on The National Alliance of Sickle Cell Centers and the Council for Change, a group funded by Pfizer Rare Disease to discuss issues faced by those living with Sickle Cell Disease.

Patricia L. Kavanagh

Member

Patricia L. Kavanagh, MD, is a board-certified pediatrician and an Associate Professor of Pediatrics at Boston University (BU) Chobanian & Avedisian School of Medicine and worked in the Pediatric Emergency Department (ED) at Boston Medical Center (BMC) for 15 years. She also is the director of pharmacovigilance at Alnylam Pharmaceuticals. Dr. Kavanagh has devoted her research career to improving the health and well-being of individuals with sickle cell disease (SCD) with funding from the National Institutes of Health, Health Resources and Services Administration, and private foundations. She has dedicated much of her career to improving ED care for children and adults with SCD. In 2015, she co-founded the Emergency Department Sickle Cell Disease Care Coalition, a national initiative to improve SCD care in the ED, which is supported by the American College of Emergency Physicians. As a physician and founder of the Emergency Department Sickle Cell Care Coalition, she testified before the Massachusetts bipartisan Committee on Financial Services in 2023 in support of an act to improve sickle cell care in the state. She was an inaugural inductee to Boston University's Clinical Excellence Society (top 2 percent of faculty) in 2017 in recognition of her work. Dr. Kavanagh served as a reviewer for the 2020 National Academies of Sciences, Engineering, and Medicine report, Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action. She formerly worked as a Senior Deputy Editor for Systematic Literature Surveillance for DynaMedex, a point-of-care tool used internationally by physicians and advanced practice practitioners to provide guidance on care for their patients based on guidelines and the best available evidence from the medical literature. Dr. Kavanagh received her medical training at BU, was a pediatric resident in the Boston Combined Residency Program, and completed a General Academic Pediatrics Fellowship at BMC.

Jerlym Porter

Member

Jerlym Porter PhD, MPH, is an Associate Member in the Department of Psychology and Biobehavioral Sciences at St. Jude Children's Research Hospital. Her involvement in sickle cell disease (SCD) initiatives includes the PhenX SCD Psychosocial and Social Determinants of Health Workgroup and co-chair of the Cure Sickle Cell Initiative (CureSCI) Patient Readiness and Resilience Working Group. As a clinical psychologist, Dr. Porter provides psychotherapeutic support for patients with SCD and their families. Her research focuses on improving the quality of life of youth with SCD through examining psychosocial outcomes, with an emphasis on healthcare transition, treatment adherence, social determinants of health, and decision making for transformative treatment options. Dr. Porter obtained a PhD in counseling psychology at Virginia Commonwealth University. She completed her doctoral internship at Rush University Medical Center and postdoctoral training at the Center for Healthcare Studies at Northwestern University, Feinberg School of Medicine. During her fellowship, she obtained an MPH within the Department of Preventive Medicine, Northwestern University, Feinberg School of Medicine.

Alexandra Power-Hays

Member

Alexandra Power-Hays, MD, is an Assistant Professor in the Division of Hematology at Cincinnati Children's Hospital. Dr. Power-Hays earned her medical degree from Harvard Medical School, then did a pediatrics residency in the Boston Children's Hospital and Boston Medical Center combined program where she was in the urban health and advocacy track and the Global Health Academy. She completed her hematology/oncology fellowship at Cincinnati Children's. She cares for children and young adults with blood diseases and leads the multidisciplinary sickle cell team in the Cincinnati Children's Health Equity Network. The network's mission is to improve equitable care for patients with sickle cell disease in Cincinnati. She also serves as a member on the Ohio Department of Medicaid's Outcomes Acceleration for Kids program, a novel state-wide effort to improve the care of children with sickle cell disease across the state. She previously served on the Health Equity Advisory Board for Novo Nordisk. She has advocated locally and nationally to dismantle barriers created by interpersonal, institutional, and structural racism on the provision of health care with specific attention to patients with sickle cell disease.

Theodore Wun

Member

Ted Wun, MD, is a Professor of Medicine and Associate Dean for Clinical and Translational Research at the University of California, Davis School of Medicine. He is Director/MPI of the NIH-funded UC Davis Clinical and Translational Science Center and Chief of the Division of Hematology and Oncology. A major clinical and research focus over the last 30 years has been sickle cell disease, which has included translational research on the role of platelet and leukocyte activation in sickle cell disease, therapeutic clinical trials, and the epidemiology of sickle cell disease related complications. He is the past Chair of the Sickle Cell Disease Advisory Committee of the National Heart, Lung, and Blood Institute. Dr. Wun is a Fellow of the American College of Physicians, and recipient of the C. John Tupper Prize for Teaching, the highest award for teaching at the UC Davis School of Medicine. He previously served as a consultant to Pfizer on an advisory board related to their sickle cell disease program and the drug Voxelotor. He received his BS/MD from the Union College/Albany Medical College Six-Year Medical Education Program, Internal Medicine and Hematology training at Harbor-UCLA Medical Center, Hematology and Oncology training at UC Davis, and bone marrow transplantation training at the City of Hope.

Jennifer I. Koop

Vice Chair

Jennifer I. Koop, PhD, (Vice Chair) is a pediatric clinical neuropsychologist and Medical Director of Neuropsychology for Children's Wisconsin. She has academic appointments at the Medical College of Wisconsin (MCW) as Professor of Neurology (Neuropsychology) and Neurosurgery. As a pediatric neuropsychologist, Dr. Koop has the specialized training and expertise to explore brain-behavior relationships and the impact that various neurological insults or diseases have on the developmental trajectory of specific cognitive functions. Clinical research activities have focused on developmental and cognitive outcomes in various clinical populations including epilepsy, brain tumors, and spina bifida. Dr. Koop is board certified in clinical neuropsychology and pediatric neuropsychology through the American Board of Professional Psychology. She currently is the chair of the American Board of Clinical Neuropsychology Subspecialty in Pediatric Clinical Neuropsychology. She has served on three prior National Academies of Sciences, Engineering, and Medicine committees sponsored by the Social Security Administration. Dr. Koop completed her PhD in Clinical Rehabilitation Psychology (focus on Neuropsychology) at Indiana University-Purdue University Indianapolis, an internship at Baylor College of Medicine/Texas Children's Hospital, and a postdoctoral fellowship at MCW.