

The National Academies of **SCIENCES • ENGINEERING • MEDICINE**

The State of the Science of Solid Organ Transplantation and Disability: A Workshop

Speaker and Moderator Biosketches

James Bowman, M.D., M.S., FACS has been a senior physician with the Division of Transplantation (HRSA) in the U.S. Department of Health and Human Services (HHS) since 2009. Dr. Bowman supports the Division's leadership in its oversight of the nation's solid organ and blood stem cell transplant programs. Previously he served as senior medical officer with Chronic Care Policy Group at CMS in support of Medicare payment policy for ERSD/dialysis units, inpatient rehab hospitals, skilled nursing facilities, home health agencies, hospital prospective payment systems and the physician fee schedule. He has medical management experience with several national health insurers and he served as a transplant and general surgeon in the US Air Force and in civilian practice. Dr. Bowman is a Fellow of the American College of Surgeons and participates with American Society of Transplant Surgeons and American Society for Blood and Marrow Transplantation. He earned his M.D. from Virginia Commonwealth University and his M.S. in Management from NC State University. He trained in general surgery at Wright State University (Dayton, Ohio) and abdominal transplant surgery at University of Pittsburgh and Children's Hospital of Pittsburgh.

Clifford Chin, M.D. is a professor of Pediatrics and the Medical Director of the Advanced Cardiomyopathy Program and Transplant Services at the Cincinnati Children's Hospital Medical Center. He completed his Pediatric training at the University of California, Davis Medical Center and Pediatric Cardiology postdoctoral fellowship at Stanford University. His academic focus has been on outcomes after transplantation including prevention of post-transplant morbidity. He has worked in a collaborative fashion with many pediatric and adult heart transplant colleagues nationally and internationally. Collaboration with those outside the field of cardiology include professionals in immunology, infectious diseases, oncology, and nephrology. Collaborative works include peer reviewed publications, university and NIH funded projects, and patient care initiatives.

Gina P. Clemons, M.G.A, Ph.D. joined the Social Security Administration (SSA) in 2011 and is currently the Associate Commissioner for the Office of Disability Policy where she leads a team of 140 who help determine national policy for SSA's disability programs. Before joining SSA, Ms. Clemons was at the Department of Veterans Affairs (VA) where, as the director of the Office of Research and Communications, she led the strategic planning efforts and the formulation of policies, procedures, and guidelines to optimize the effectiveness of VA's research programs. Ms. Clemons also has an extensive 13-year work history at the Centers for Medicare and Medicaid Services (CMS) where, among other positions, she served as national director for the End Stage Renal Disease Network Program and director within the Disabled and Elderly Health Programs Group. Ms. Clemons was also the CMS Medicare/Medicaid dual eligible, limited English proficiency, and homelessness agency lead.

Prior to her positions within the Federal Government, as the national director of provider relations for Dental Benefit Providers, Ms. Clemons was responsible for overseeing the provider relations activities in twenty-four states, and served as faculty member and research coordinator at the University of Maryland Dental School. She earned her Masters of General Administration, with a Health Care Administration concentration, and her PhD in Health Care Public Policy through the University of Maryland system. Ms. Clemons is a disabled Veteran of the United States Army.

Carol Conrad, M.D. joined clinical faculty at Stanford Children's Health/Lucile Packard Children's Hospital in 1995. Her training in pediatric (and adult) lung transplant began informally in 2004, and was named Director of the program in 2007. The program separated from the adult service in 2009, and is the only pediatric program on the West Coast, west of Texas. The team performs 3 pediatric lung or heart-lung transplants per year, on average to treat CF, pulmonary hypertension, and some congenital vascular malformations that lead to pulmonary hypertension. Dr. Conrad's center has participated in national multicenter clinical research projects under the aegis of the CTOTC (Clinical Trials in Organ Transplant in Children) funding mechanism of the NIH to discover mechanisms of Lung Graft Failure in children. Dr. Conrad served as Chair of the Pediatric Scientific Council of the International Society of Heart and Lung Transplantation (ISHLT) from 2019-2020, which then, under a re-organization business plan, is now the representative of the Pediatric Lung Transplant Professional Community to the Advanced Lung Failure and Transplant steering committee. Dr. Conrad attended the Drew-UCLA Medical Education Program from 1985 – 1989 and did her residency at The Los Angeles Children's Hospital Resident in Pediatrics from 1989 – 1992. Dr. Conrad was a Postdoctoral Fellow from 7/1992 – 7/1995 in the Division of Pediatric Pulmonary Medicine at The Johns Hopkins University School of Medicine.

Andrea DiMartini, M.D. is a Professor of Psychiatry and Surgery at the Starzl Transplant Institute at the University Of Pittsburgh Medical Center. She completed her medical school training at the University Of Chicago Pritzker School Of Medicine and her residency training at the Western Psychiatric Institute. She has nearly 30 years of clinical and research experience working with the solid organ transplant teams at the Starzl Transplant Institute. She is considered an expert in transplant psychiatry and has written extensively and lectures both nationally and internationally on transplant psychiatry issues. She has been awarded several National Institutes of Health grants to conduct longitudinal research on patients' mental health and behavioral outcomes following transplantation.

Dawn P. Edwards is a self-described 27 Year Chronic Kidney Disease Warrior. Dawn has experienced first-hand every renal replacement modality including a kidney transplant and rejection. She is currently a Nocturnal Home Hemodialysis patient. As a result, she has a plethora of insight into the needs of people with Chronic Kidney Disease, always keeping in mind that patients need different things at different times in their lives. Dawn is dedicated to improving the quality of life of people with kidney disease, and is also a resource to her community, sharing her story and educating people about the relationship between hypertension, diabetes and kidney disease, especially among underserved communities.

Dawn has served the community for over 25 years through the IPRO ESRD Network of New York as a communicator, mentor and educator, she serves on many kidney disease related boards and has reinvented herself by working as a Patient Advocate for Fresenius/NxStage and a Wellness Ambassador for the Rogosin Institute. Dawn is also the Co- Chairperson of the Forum of ESRD Networks Patient Advisory Council (KPAC), is actively involved with the National Kidney Foundation and American Association of Kidney Patients, serves as Patient Advisor for Studies with the NIH/NIDDK and is the CEO of her own Advocacy and Education Organization, the New York State CKD Champions, whose motto is to Educate, Encourage and Empower. She believes that Faith Family and Education are the keys to her longevity, and every day is an opportunity to thrive, not just survive. Dawn recently co-authored an article in the January 2021 issue of Clinical Journal of the American Society of Nephrology (CJASN) titled, Personal Experiences of Patients in the Interaction of Culture and Kidney Disease.

John A. Goss, M.D., FACS, is a professor of surgery in the Michael E. DeBakey Department of Surgery at Baylor College of Medicine and chief of the division of Abdominal Transplantation. He specializes in adult and pediatric liver transplantation, hepatobiliary surgery, and surgical management of liver tumors. He is board certified by the American Board of Surgery and is a fellow of the American College of Surgery. After earning his medical degree from Creighton University in Omaha, Nebraska, Dr. Goss completed his general surgical residency at the Washington University School of Medicine Surgical Program. He then completed a 2-year multi-organ transplant fellowship in the Division of Liver and Pancreas Transplantation at the University of California School of Medicine in Los Angeles (UCLA). Dr. Goss has performed many surgical "firsts" in Houston, including the first split liver adult and pediatric transplants, the first adult living donor liver transplant, the first dual organ lung-liver transplant, and the first dual organ heart-liver transplant.

Aditi Gupta, M.D. is a nephrologist and a clinical investigator with the long-term goal of pursuing impactful patient-oriented research in vascular risk reduction and dementia. After her training in internal medicine and nephrology, she started her career on the Clinical Educator track and with focus on clinical care and education. Having trained in the same program, she had the opportunity to follow many patients over years and struggle with cognitive impairment and report improvement in cognition after a kidney transplant. These clinical observations inspired her to change her career path and immerse in clinical research. Dr. Gupta crossed interdepartmental boundaries, developed multidisciplinary collaborations and embarked on challenging 'out of the box' studies with their successful completion. She received pilot grant awards from The Kidney Institute at the University of Kansas Medical Center, the Frontiers Pilot and Collaborative Studies Funding

Program and The Office of Scholarly, Academic & Research Mentoring (OSARM). These led to an NIH K23 award in 2017 to examine cognition and brain changes pre-to-post kidney transplant to elucidate mechanisms underlying cognitive impairment in kidney disease. She has presented several abstracts and recently published a manuscript on brain changes pre-to post-transplant in the Journal of American Society of Nephrology, a leading nephrology journal. She has two other investigator-initiated studies evaluating changes in cerebral blood flow with calcineurin inhibitors to understand observations of decrease in cerebral blood flow after transplantation in the K23 study. She has several studies investigating the prevalence of cognitive impairment in kidney transplantation and impact of cognitive impairment on candidacy for kidney transplantation. To further her research goals, and bring changes in the real world in actual clinics, she received training in implementation science. This knowledge led to the NIH R61/R33 award "Remote Monitoring and Virtual Collaborative Care for Hypertension Control to Prevent Cognitive Decline" funded in 2020. In this pragmatic study she is testing a new hypertension program to achieve goal blood pressure to prevent cognitive decline.

Nitika Gupta, M.D., DCH, DNB, MRCPH is a triple board-certified Pediatric Gastroenterologist and Transplant Hepatologist in the Department of Pediatrics, Emory University School of Medicine and Children's Healthcare of Atlanta. She did her pediatric residency, pediatric gastroenterology and transplant hepatology fellowships at Emory University. Over the past 20 years, the focus of her work has been in liver diseases of children and liver transplantation. She conducts basic, clinical and translational research in pediatric liver transplantation and Immune mediated liver disease of children such as autoimmune hepatitis and primary sclerosing cholangitis. She has received several honors for her work and has published well-cited articles. She has a special interest in transition of care of pediatric to adult healthcare and was the founding director of the adolescent transition program for liver transplant recipients. She also established a joint clinic between the pediatric and adult healthcare systems resulting in improved graft and patient survival after transition. She has a strong focus on connecting the bench to the bedside with the overall goal of developing strategies and treatment options to improve the quality of life of children with liver disease and liver transplant. Being in the south east a significant proportion of her patients are from minority backgrounds and her recent research has demonstrated that significant racial disparities exist in the African American children with liver disease and liver transplant with high risk of mortality after transfer from pediatric to adult healthcare. She has developed new interventions and programs to help mitigate these risks resulting in improved outcomes. She is a member of the Diversity, Equity, and Inclusion councils of Children's healthcare of Atlanta and Emory University School of Medicine. She is interested in education and has mentored several undergraduates, medical students, residents and fellows for laboratory and clinical research. She also serves on the Emory University senate which oversees activities of Emory University which includes several schools. She is on the American Board of Medical Specialties (ABMS) stakeholder committee and was selected to serve on the Vision commission of the ABMS which was charged with developing a roadmap for the future of board certification of US diplomats.

Stephanie Hoyt-Trapp, Ph.D., is a clinical-community psychologist. She received a new liver about 6 years ago after being diagnosed with nonalcoholic steatosis hepatitis. Severe depression and ongoing medical complications have made her transplant journey quite difficult. Having portal hypertension, internal bleeding, encephalopathy, and an occluded hepatic vein are some of the medical conditions she has faced. Dr. Hoyt-trapp is currently working part time as a consulting psychologist on a grant regarding pain and cirrhosis.

Valen Keefer toes the line every day between survival and advocacy. At the age of 38, she is thriving thanks to two lifesaving transplants. A kidney when she was 19 and a liver transplant at 35. Both needed because of polycystic kidney disease (PKD). Valen has endured an arduous health journey full of hospital stays and illness. She has undergone 30 surgeries and has more than 60 inches of scars crisscrossing her body. Despite life challenging her at nearly every turn, Valen is determined to help others who are fated to walk a similar path and be the role model she wishes she had. She has taken her new lease on life and is intent on paying it back tenfold. As a passionate patient advocate since 2004, she works tirelessly to raise awareness of kidney disease, PKD and organ donation and to help educate and empower others.

Grounded in gratitude, Valen works directly with countless patients and has shared her extraordinary story at over 100 events across North America with an authentic optimism that inspires people and moves them to action. She's done many press interviews, coordinated educational and fundraising events and helped raise over \$1,000,000 for polycystic kidney disease research. Valen has written hundreds of blogs (published by non-profits), painting a genuine picture of the challenges and joys of this journey. Through her collaborations with numerous organizations, she has inspired a combined total of 1.7 million social media followers with her story of hope and resilience that transforms people forever. Valen has a way of connecting and touching the hearts and minds of all she meets and her journey has become a beacon of hope for countless people around the world. She proves there is not just life post-transplant and with severe kidney disease, but potentially a great one.

Paul Kimmel, M.D., MACP, FRCP, FASN, has made significant contributions in patient care, research, and service to professional organizations. He has been a faculty member in the department of medicine at George Washington University in Washington, DC, since 1983. He was director of the division of renal diseases and hypertension at George Washington University Medical Center from 2001 to 2006. Dr. Kimmel served as the director of education for ASN from 2006 to 2007 and joined the National Institute of Diabetes, Digestive and Kidney Diseases, National Institutes of Health in 2008. He currently serves as senior advisor to the director of the Division of Kidney, Urologic, and Hematologic Diseases, where he has managed programs in HIV-associated kidney disease, acute kidney injury, clinical genetics of kidney disease, kidney precision medicine, clinical outcomes of kidney organ donation by African-Americans, and opioid use in dialysis patients. His research interests include sleep disorders, quality of life, and psychosocial issues (including depression, anxiety, and perception of social support) in ESKD and CKD patients. He is also interested in HIV-associated kidney diseases, long-term outcomes of acute kidney injury, perception of pain, and inflammatory and immunologic factors mediating outcomes in patients with kidney failure. He has recently fostered patient and community engagement in clinical research. He has published more than 300 papers, edited two monographs, and edited two editions of the textbook Chronic Renal Disease. Dr. Kimmel has served on the editorial boards of Blood Purification, American Journal of Kidney Diseases, JASN, and CJASN. He was recently inducted as a fellow of the Royal College of Physicians in London and is a master of the American College of Physicians. He served as a board member and president of the Academy of Medicine of Washington, DC. He received the Belding H. Scribner MD Memorial award from the ASN in 2019. Dr. Kimmel received his medical degree from the New York University School of Medicine and trained in internal medicine at Bellevue Hospital in New York City. He completed a fellowship in renal and electrolyte disorders at the University of Pennsylvania hospital and stayed there as a faculty member until joining George Washington University.

Erika D. Lease, M.D., FCCP, is the Medical Director of the University of Washington Lung Transplant Program and Associate Professor of Medicine within the Division of Pulmonary, Critical Care, and Sleep Medicine at the University of Washington. In addition to her work with the Lung Transplant program, Dr. Lease also specializes in infectious diseases relating to all solid organ transplant recipients and is an attending with the Solid Organ Transplant Infectious Disease program. Her research interests include lung transplant, solid organ transplant, and infectious diseases.

Sunita Mathur, P.T., Ph.D. is physical therapist and an Associate Professor in the Department of Physical Therapy at the University of Toronto. She directs the Muscle Function and Performance Lab, and conducts research on skeletal muscle dysfunction and sarcopenia in people with chronic lung disease and solid organ transplant candidates and recipients. The goals of the research program are to understand the link between muscle structure and function, the relationship between sarcopenia and clinical outcomes, and the effect of exercise training on improving muscle dysfunction. Dr. Mathur has published over 100 peer-reviewed articles and holds grant funding from the Canadian Institutes of Health Research, The Lung Foundation and the Canadian Thoracic Society.

Dr. Mathur is the co-founder and co-Chair of CAN-RESTORE, which is a national network dedicated to achieving optimal well-being in transplant patients through exercise and rehabilitation. She is also an investigator with the Canadian Donation and Transplantation Research Program (CDTRP), and co-lead for the research theme on restoring long term health after transplant.

George V. Mazariegos, M.D., FACS, FAST, is the Division Chief of Pediatric Transplantation at UPMC Children's Hospital of Pittsburgh, the Hillman Center for Pediatric Transplantation, the Thomas E. Starzl Transplantation Institute. He is a Professor at the University of Pittsburgh in the departments of Surgery, Anesthesiology and Critical Care Medicine and holds the Jamie Lee Curtis Chair in Pediatric Transplantation Surgery. Dr. Mazariegos earned a bachelor's degree in medical science at Northwestern University in Evanston, Ill., in 1984. He graduated from Northwestern University Medical School. He completed residency training at Michigan State University in Grand Rapids and completed his fellowship training at the University of Pittsburgh in 1993. Dr. Mazariegos has been involved in the academic field of transplantation surgery for more than 25 years and has served as the past Chair of the Society of Pediatric Liver Transplantation, the immediate past President of the International Intestinal Rehabilitation and Transplant Association (IRTA), counselor for the International Pediatric Transplant Association (IPTA) and immediate past Chair of the UNOS OPTN pediatric committee. Dr. Mazariegos specializes in the treatment of pediatric patients who have liver and/or intestinal disease that require transplantation. He also cares for children who develop acute liver failure and who may require specialized liver support therapies until they recover or until donor organs are available. He is a member of the International Liver Transplant Society and an active member of the Society of University Surgeons and Association of the American Surgical Association. Recently, Dr. Mazariegos and colleagues founded the Starzl Network for Excellence in Pediatric Transplantation (www.starzltransplantnetwork.com), a consortium bringing innovation and tech partners together with patients, families and transplant centers to transform outcomes in children undergoing transplantation. Dr. Mazariegos has authored or co-authored more than 265 original articles, more than 230 abstracts and 20 book chapters.

Mara McAdams DeMarco, Ph.D., M.S. is an Associate Professor of Epidemiology and Surgery on faculty at Johns Hopkins School of Medicine. She has a joint appointment in the Department of Epidemiology at the Johns Hopkins Bloomberg School of Public Health. She is also the Director of Clinical and Outcomes Research for the Department of Surgery and the Director of the Johns Hopkins Surgery Center for Outcomes Research and through these roles she collaborate with many clinical faculty, including nephrologists, transplant surgeons and geriatricians, across JHU and other universities. She has published over 130 manuscripts with over half being co-authored by trainees and is the PI of three NIH-funded R01 studies. Her research focuses on the intersection of aging and end-stage renal disease (ESRD) with a particular focus on older kidney transplant candidates and recipients. She has conducted some of the first studies of frailty, delirium, cognitive function, and Alzheimer's disease among older kidney transplant patients. She is the PI of the oldest and largest cohort study of frailty among kidney transplant candidates and recipients and clinical trials of exercise interventions. Her career objectives are to better understand how novel aging metrics (frailty, cognitive function, physical function and quality of life) can help improve risk prediction of adverse outcomes in older kidney transplant recipients and identify novel interventions to prevent adverse outcomes of aging.

Melissa McQueen is Executive Director of Transplant Families who works with parents and caregivers of children being listed for or already have received a lifesaving organ transplant to help guide them to support, education, and assistance to help them through this very difficult time.

Melissa believes that education and support bring hope and healing for families. She is honored to volunteer with the OPTN/UNOS in their Pediatric Committee and their Data Advisory Committee where she helped co-author "What Every Parent Needs to Know". She has also been selected as leadership with Quality Improvement Collaboratives ACTION Learning Network (pediatric cardiac QI based out of Cincinnati Children's Hospital) and Starzl Learning Network (pediatric liver QI based out of University of Pittsburgh Medical Center) to give input and help co-create materials for clinicians and families. She worked on the spearheading committee that helped Donate Life America create National Pediatric Transplant Week (during the last week of every April). She is the charter chair of the Heart Center Family Advisory Council and Alumni Family Advisory Council at Phoenix Children's Hospital.

Melissa is a trained developer/engineer by trade who has worked at companies such as Honeywell - Aeronautics Division, APS, Wells Fargo, and Phoenix Children's Hospital. Most recently, she helped to develop "My journey with" applications covering patient education from diabetes to transplant for newly diagnosed families. Melissa holds a Bachelor's in Computer Information Systems from DeVry University.

Saeed Mohammad, M.D., M.S., cares for children with liver diseases, including those who may need a liver transplant. He has a great team who works hard to provide reassurance and care for both patients and their families during the stress of a critical illness, and he is extremely proud to work with them. Dr. Mohammad enjoys the long term relationships that have developed with many of his patients and their families and is grateful to be a part of their lives.

Dr. Mohammad's research work is focused on improving the long term outcomes and quality of life of children with chronic illnesses particularly pediatric liver transplant recipients. His team is studying ways to improve the lives of these patients beyond standard medical therapy through the measurement of serum biomarkers and personalizing treatment.

Robert A. Montgomery, M.D., DPhil, FACS is the Chairman and Professor of Surgery at NYU Langone Health and the Director of the NYU Langone Transplant Institute. He received his Doctor of Medicine with Honor from the University of Rochester School of Medicine. He received his Doctor of Philosophy from Balliol College, The University of Oxford, England in Molecular Immunology. Montgomery completed his general surgical training, multi-organ transplantation fellowship, and postdoctoral fellowship in Human Molecular Genetics at Johns Hopkins. For over a decade he served as the Chief of Transplant Surgery and the Director of the Comprehensive Transplant Center at Johns Hopkins.

Dr. Montgomery was part of the team that developed the laparoscopic procedure for live kidney donation, a procedure that has become the standard throughout the world. He and the Hopkins team conceived the idea of the Domino Paired Donation (kidney swaps), the Hopkins protocol for desensitization of incompatible kidney transplant patients, and performed the first chain of transplants started by an altruistic donor. He led the team that performed the first 2-way domino paired donation, 3-way paired donation, 3-way domino paired donation, 4-way paired donation, 4-way domino paired donation, 5-way domino paired donation, 6-way domino paired donation, 8-way multi-institutional domino paired donation, and co-led the first 10-way open chain. He is credited in the 2010 Guinness Book of World Records with the most kidney transplants performed in 1 day. He is considered a world expert on kidney transplantation for highly sensitized and ABO incompatible patients and is referred the most complex patients from around the globe.

Dr. Montgomery has had clinical and basic science research supported by the NIH throughout his career. He has authored 300 peer reviewed articles, cited more than 26,000 times and has an h-index of 84. His academic interests include HLA sensitization, tolerance protocols including simultaneous solid organ and bone marrow transplantation, bioartificial organs and xenotransplantation. He has received important awards and distinctions including a Fulbright Scholarship and a Thomas J. Watson Fellowship and memberships in the Phi Beta Kappa and Alpha Omega Alpha academic honor societies. He has been awarded multiple scholarships from The American College of Surgeons and The American Society of Transplant Surgeons. The National Kidney Foundation of Maryland has recognized his contributions to the field of transplantation with the Champion of Hope Award, the National Kidney Registry with the Terasaki Medical Innovation Award and The Greater New York Hospital Association with the Profile in Courage Award. He is also became the recipient of a heart transplant in 2018.

David Mulligan, M.D., FACS is a Professor and Chair of Transplantation and Immunology at Yale University, skilled in Liver Transplantation (especially Living Donor Liver Transplant), Kidney & Pancreas Transplantation, Hepatobiliary Surgery, and Immunology. Dr. Mulligan graduated from University of Louisville School of Medicine. Honored to build the Multiorgan Transplant Program at Mayo Clinic in Arizona from 1998-2013 with outstanding growth in all solid organ transplantation with some of the best outcomes in the US. Transforming the Multiorgan transplant program at Yale to be one of the most innovative and academic institutions where patient centered care can be met with cutting edge research and science. Recently elected President of UNOS/OPTN and Chair of the Advisory Council on Transplantation to the Secretary of HHS to lead the oversight and policy development of organ transplantation in the United States. Also serving as Councilor at Large for the Board of Governors of the AASLD and Chair of the Business Practice Services Committee of the ASTS. Heavily involved in developing new policies and guidance across all organ transplantation and allocation during the COVID-19 pandemic for the safest possible outcomes for patients as well as providers.

Jignesh K. Patel, M.D., Ph.D., FACC, FRCP, FAST, FAHA is Clinical Professor of Medicine, Medical Director of Heart Transplant, Director of the Cardiac Amyloid Program, and Director of Heart Transplant Research at Cedars-Sinai Smidt Heart Institute, Los Angeles, CA.

His clinical and research interests focus on cardiac amyloidosis and transplant immunology. Dr Patel serves on the Leadership Advisory Forum and is past-Chair of the Heart Failure and Transplantation Council of the ISHLT. He serves on the Heart Failure and Transplantation Leadership Council at the American College of Cardiology. He is Associate Editor of American Journal of Transplantation and Current Transplantation Reports.

Tanjala S. Purnell, Ph.D., M.P.H. Tanjala Purnell PhD, MPH is an epidemiologist and health services researcher with over a decade of research experience related to identifying and addressing patient/family, healthcare system, and community factors influencing health and healthcare disparities for adults with cardiovascular disease risk factors, including hypertension, chronic kidney disease, and diabetes. She is an Assistant Professor of Cardiovascular Disease and Clinical Epidemiology at the Johns Hopkins Bloomberg School of Public Health. She holds joint faculty appointments in the Johns Hopkins Departments of Surgery, Health Policy and Management, and Health Behavior and Society.

In her role as an Associate Director of the Johns Hopkins Urban Health Institute, Dr. Purnell co-leads the institute's efforts to facilitate and recognize collaborations between communities, universities, healthcare delivery systems, government, and the private sector to build collective capacity for achieving health equity in Baltimore. She is also the Associate Director for Education and Training at the Johns Hopkins Center for Health Equity, where she leads the center's award-winning educational and training programs for public health, nursing, and medical scholars working to advance health equity. In addition, she is the director of community and stakeholder engagement for the Hopkins Epidemiology Research Group in Organ Transplantation, core faculty at the Welch Center for Prevention, Epidemiology and Clinical Research, and affiliated faculty with the Bloomberg American Health Initiative and the Center for Health Services and Outcomes Research.

Nationally, Dr. Purnell serves as the Chair of the American Society of Transplant Surgeons (ASTS) Diversity, Equity, and Inclusion Committee, and she previously served as Region 2 Representative to the OPTN/UNOS Minority Affairs Committee. She is a native of the Mississippi Delta and an alumna of Tougaloo College where she obtained her B.S. in Computer Science. Purnell has received several national and international research honors and has published findings from her work in leading medical and public health journals, including JAMA, Health Affairs, Journal of the American Society of Nephrology, American Journal of Hypertension, American Journal of Transplantation, and Diabetes Care. She is deeply committed to community engagement, teaching, and mentoring, and she speaks often on the impact of COVID-19 and systemic racism on existing health and healthcare disparities in the United States. She is also the recipient of multiple Teaching Excellence Awards from the Johns Hopkins Bloomberg School of Public Health.

Shari Rogal, M.D., M.P.H., is Assistant Professor of Medicine and Surgery, University of Pittsburgh and Core Member of the Center for Health Equity Research and Promotion, VA Health System, Pittsburgh, PA. Dr. Rogal is a transplant hepatologist whose clinical research focuses on addressing the psychosocial contributions to quality of life and transplant outcomes. She identified an association between untreated depression and increased post-transplant rejection and mortality. Depression is associated with pain and both conditions are often suboptimally managed in transplant populations. Dr. Rogal is currently developing and implementing a program to increase evidence-based management of these symptoms in the peri-transplant period. Dr. Rogal also works in implementation science more broadly and has developed novel methods to assess the contributions of implementation strategies to the quality and equity of care.

Sara Rosenbaum, J.D., is the Harold and Jane Hirsh Professor of Health Law and Policy and Founding Chair of the Department of Health Policy at the Milken Institute School of Public Health, George Washington University. She also holds professorships in the Trachtenberg School of Public Policy and Public Administration and the Schools of Law and Medicine and Health Sciences. A graduate of Wesleyan University and Boston University Law School, Professor Rosenbaum has devoted her career to issues of health justice for populations who are medically underserved as a result of race, poverty, disability, or cultural exclusion. An honored teacher and scholar, a highly popular speaker, and a widely-read writer on many aspects of health law and policy, Professor Rosenbaum has emphasized public engagement as a core element of her professional life, providing public service to six Presidential Administrations and nineteen Congresses. She is best known for her work on national health reform, Medicaid and private insurance, Medicaid managed care, health care access for medically underserved communities and populations, and civil rights and health care. Professor Rosenbaum's current research focuses on the transformation of Medicaid and its effects on poor populations and communities. Her research also focuses on national health reform, Medicaid managed care, and the nation's community health centers, the largest primary health care system for medically underserved rural and urban populations. She is best known for her research into the impact of laws affecting health care access and coverage, as well as the potential effects of major shifts in laws affecting low income and medically underserved populations.

Dorry Segev, M.D., Ph.D., is the Marjory K. and Thomas Pozefsky Professor of Surgery and Epidemiology and Associate Vice Chair of Surgery at Johns Hopkins University. He is the founder and director of the Epidemiology Research Group in Organ Transplantation (ERGOT). Dr. Segev was the first to demonstrate the survival benefit of incompatible kidney transplantation across the United States and is responsible for the first HIV-to-HIV transplants in the United States. His NIH-funded research includes kidney exchange, desensitization, long-term donor risk, access to transplantation, expanding transplantation including HIV+ donors, geographic disparities, post-transplant outcomes, and the intersection between transplantation and gerontology. Dr. Segev focuses on novel statistical and mathematical methods for simulation of medical data, analysis of large healthcare datasets, and outcomes research. Dr. Segev has published nearly 500 peer-reviewed research articles and he was recently awarded the American Society of Transplantation's Clinical Science Investigator Award. He is a current councilor of the American Society of Transplant Surgeons and former chair of the American Transplant Congress. His work has directly influenced policy, including two Congressional bills (the Norwood Act for kidney exchange and the HOPE Act for HIV-to-HIV transplants). Dr. Segev is most inspired by his role as a mentor, having mentored over 100 graduate students, residents, and faculty, and is the only general surgeon in the US funded by an NIH/NIDDK Mentoring Grant.

Eyal Shemesh, M.D. is the chief of the Division of Behavioral and Developmental Pediatrics at the Kravis Children's Hospital and professor in the Departments of Pediatrics and Psychiatry at the Icahn School of Medicine at Mount Sinai in New York. Dr. Shemesh trained in the Mount Sinai "Triple Board" program as a pediatrician, psychiatrist, and a child psychiatrist. Since graduating from the triple-board residency program, he has been continuously funded by Federal and Philanthropic entities to conduct research in the interface between psychiatric / behavioral and medical disorders, with non-adherence as the important outcome, in children and adults. Amongst other areas of research concentration, Dr. Shemesh and his group discovered, studied, and developed the use of variation in medication blood levels as a marker of non-adherence (the Medication Level Variability Index) in transplant recipients, and have been studying the impact of traumatic stress symptoms on several groups of chronically ill patients including transplant recipients. In addition to this research work, Dr. Shemesh has created and has been directing specialty programs that enhance patients' access to mental health care by integrating mental health concepts into the work of specialty and primary care clinics in pediatric and adult practices.

Charlie Thomas, LCSW, ACSW, FNKF Received his Master of Social Work Degree from Arizona State University in 1980 and his Bachelor of Arts in 1979 from San Diego State University where he graduated with Distinction in Social Welfare. He is a Licensed Clinical Social Worker (LCSW) in Arizona and a member of the National Association of Social Workers (NASW) Academy of Certified Social Workers (ACSW). He has been employed as a transplant social worker with Banner University Medical Center in Phoenix, Arizona since 1985 and was the Dialysis/Transplant Consultant for the Salt River Pima-Maricopa Indian Community 1998 to 2012. He provides direct services to liver, kidney and pancreas transplant patients as well as living kidney and liver donors. He also provided consultation regarding Chronic Kidney Disease including dialysis, transplantation and organ donation with American Indians.

Mr. Thomas has served with many national and regional organizations including 1) the American Society for Transplantation Public Policy Committee, 2) the National Kidney Foundation Board of Directors while serving as national chairperson of the NKF Council of Nephrology Social Workers, and the NKF Public Policy Task Force which developed the NKF Public Policy Office in Washington, D.C., 3) the NKF of Arizona Board of Directors since 1988 and several affiliate committees including Patient Services, Nephrology conference and others, 4) the Medical Review Board of the Intermountain ESRD Network, 5) the United Network for Organ Sharing (UNOS) Patient Affairs Committee, the Task Force on Access to Transplantation and chairperson of the Social Work Advisory Task Force, 6) the National Living Donor Consensus Conference and 7) the Arizona Coalition on Donation as president among many others. In 1999 Charlie was selected to serve as an expert advisor to the Institute of Medicine regarding the proposed Final Rule for the Organ Procurement and Transplant Network (OPTN). In 2000 Arizona Governor Jane Hull appointed Charlie to serve on the Governor's State Rehabilitation Council which advises the Arizona Vocational Rehabilitation Program. He served as Chair of the Council from 2003-2005. Charlie is active in advocating for the removal of health insurance as a barrier to returning to work for the disabled.

Mr. Thomas teaches Social Welfare Policy and Community Practice to graduate and undergraduate social work students at Arizona State University. He has authored many articles and has presented at many national conferences and meetings. In 2000 the Phoenix Business Journal profiled Charlie as one of the "People Making a Difference". In the interview he states that advocating for the expansion of the State Medicaid program to cover heart, heart-lung, lung, liver and bone marrow transplants for the working poor was his most significant accomplishment. The advocacy also resulted in the provision of allowing patients waiting for transplants to remain on the waiting list even if they lost their Medicaid eligibility. He has organized a coalition of transplant hospitals and related non profit health associations to promote living donor leave for Arizona State employees and was successful when the 2008 Arizona State Legislature passed legislation and it was signed by the Governor. In 2006 he was awarded the 2006 Health Care Heroes Award-Non Physician by the Phoenix Business Journal. In 2015 he received the Robert W. Whitlock Lifetime Achievement Award from the NKF Council of Nephrology Social Workers and in 2020 received the Clinician of Distinction Award from the American Society of Transplantation. In 2007 Mr. Thomas was recruited by the Centers for Medicare and Medicaid Services to train CMS surveyors regarding the psychosocial issues of organ transplant recipients and living donors.

Hannah Valantine, M.D., MRCP, FACC received her M.B.B.S. degree (Bachelor of Medicine, Bachelor of Surgery; the United Kingdom's equivalent to an M.D.) from St. George's Hospital, London University in 1978. After that, she moved to the University of Hong Kong Medical School for specialty training in elective surgery before returning to the U.K. She was awarded a diploma of membership by the Royal College of Physicians (M.R.C.P.) in 1981. In addition, she completed postgraduate training and numerous fellowships, serving as senior house officer in Cardiology at Brompton Hospital and Registrar in Cardiology and General Medicine at Hammersmith Hospital. In 1985, Dr. Valantine moved to the United States for postdoctoral training in cardiology at Stanford University, and in 1988, she received a Doctor of Science (DSc), Medicine, from London University. Dr. Valantine became a Clinical Assistant Professor in the Cardiology Division at Stanford and rose through the academic ranks to become a full Professor of Medicine in the

Division of Cardiovascular Medicine and Director of Heart Transplantation Research. She came to the NHLBI in 2014 to continue her research while also serving as the first NIH Chief Officer of Scientific Workforce Diversity. Dr. Valantine has received numerous awards throughout her career including a Best Doctor in America honor in 2002. She has authored more than 160 primary research articles and reviews and previously served on the editorial boards of the journals *Graft* and *Ethnicity & Disease*. Dr. Valantine is a member of the American College of Cardiology, the American Society of Transplant Physicians, and the American Heart Association, and past President of the American Heart Association Western States Affiliate.

Fanny Vlahos, J.D., LL.B., B.A. is a cystic fibrosis patient who underwent a double lung transplant in 2012, when her son was only 10 months old. She is a licensed attorney (IL) and holds degrees in American and Canadian law as well as an undergraduate degree in English Language & Literature, with Honors. In recent years, Fanny has used her unique position to champion for access to quality health care and is involved with the Cystic Fibrosis Foundation on the National Guidelines Committee, the Lung Transplant Initiative, and the Steering Committee, among others. She has dedicated her efforts to public policy advocacy at both the state and national level. Fanny currently resides in the Chicago area with her husband, their rescue dog and her main motivation and pride and joy, their son.

Kirsten Wentlandt, M.D., Ph.D., M.HSc. is a palliative care physician from the University of Toronto, and is the W. Gifford-Jones Professor in Pain Control and Palliative Care, and Head of the Division of Palliative Care. Her clinical work and research are focused on nonmalignant palliative care populations, with ambulatory clinics supporting advanced lung, heart, pulmonary hypertension and transplant populations. She also works with various national, provincial and regional committees that focus on developing strategies to improve access to quality palliative care for all patients.