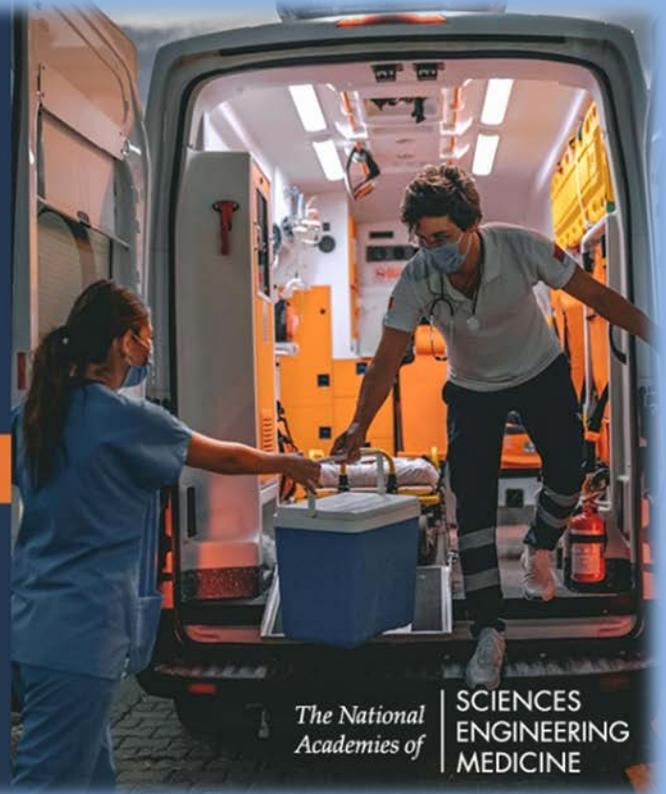


A FAIRER AND MORE
EQUITABLE, COST-EFFECTIVE, AND
TRANSPARENT SYSTEM OF
**DONOR ORGAN PROCUREMENT,
ALLOCATION, AND DISTRIBUTION**

A Public Workshop of the Committee

FEBRUARY 4 (10AM-4PM ET)

FEBRUARY 5 (10AM-3PM ET)



*The National
Academies of* SCIENCES
ENGINEERING
MEDICINE

Briefing Book

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

HEALTH AND MEDICINE DIVISION
Board on Health Sciences Policy
Board on Health Care Services

**The Committee on A Fairer and More Equitable, Cost-Effective,
and Transparent System of Donor Organ Procurement, Allocation,
and Distribution: Public Workshop**

February 4 & 5, 2021

Virtual Public Workshop

**BRIEFING BOOK
TABLE OF CONTENTS**

I: Agenda

1. Agenda for Public Workshop

II: Committee

1. Statement of Task
2. Committee Roster
3. Committee and Staff Biosketches

III: Workshop Sessions

1. Speaker Bios
2. Session Questions
3. Bibliography of Speaker-Suggested Resources

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HEALTH AND MEDICINE DIVISION
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February 4 & 5, 2021
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TAB I

AGENDA

The National Academies of
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HEALTH AND MEDICINE DIVISION
Board on Health Sciences Policy
Board on Health Care Services

**The Committee on A Fairer and More Equitable, Cost-Effective, and
Transparent System of Donor Organ Procurement, Allocation, and
Distribution: Public Workshop**

February 4 & 5, 2021
Virtual Public Workshop

TIMELINE:

Day 1 – Thursday, February 4: 10:00 AM – 4:00 PM ET
Day 2 – Friday, February 5: 10:00 AM – 3:00 PM ET

DAY 1: Thursday, February 4, 2021

10:00 a.m. **Introduction and Charge to the Workshop Speakers and Participants**

KENNETH W. KIZER, *Committee Chair*
Chief Healthcare Transformation Officer
Senior Executive Vice President
Atlas Research

**SESSION I. BIOETHICAL CONSIDERATIONS OF FAIRNESS, EQUITY, AND
TRANSPARENCY**

Session Chair: KENNETH KIZER, *Committee Chair*

Session Objectives:

- To discuss the bioethical considerations of fairness, equity, and transparency in deceased donor organ procurement, allocation, and distribution.
- Consider what the terms “fairness”, “equitable”, and “transparency” currently mean when applied to the deceased donor transplant system.

10:05 a.m. **Bioethical Underpinnings of a Fair, Equitable, and Transparent Deceased Donor
Organ Procurement, Allocation, and Distribution System**

JAMES CHILDRESS
Professor Emeritus, University Professor and John Allen Hollingsworth Professor
of Ethics, and Professor of Religious Studies
University of Virginia

10:15 a.m. **Examining the Legal Underpinnings of the Transplant System – Are there Inherent Barriers to Fairness, Equity, Transparency?**

ALEXANDRA GLAZIER
CEO
New England Donor Services

10:25 a.m. **Discussion with Committee (20 mins)**

SESSION II. THE U.S. ORGAN PROCUREMENT SYSTEM

Session Chair: SUE DUNN, *Committee Member*

Session Objectives:

- Discuss OPO processes and systems that ensure fairness and equity in organ donation.
- Describe innovative OPO practices that have led to increased organ donation and transplant.

10:45 a.m. **Overview of the Organ Procurement Process**

HOWARD NATHAN
CEO
Gift of Life (Philadelphia)

SUSAN GUNDERSON
CEO
LifeSource (Minneapolis)

11:05 a.m. **Discussion with Committee (15 mins)**

11:20 a.m. **Organ Utilization – OPO Challenges and Approaches**

KEVIN O'CONNOR
CEO
LifeCenter Northwest (Seattle)

RICHARD PEREZ
Medical Director, Transplant Center
University of California, Davis

11:40 a.m. **Discussion with Committee (15 mins)**

11:55 a.m. **Panel Discussion: Innovation in the Organ Procurement Process**

Panel Objectives:

- Explore the role of OPOs in community acceptance of organ donation to help address inequities and disparities within the system.
- Discuss a range of innovative practices within OPOs to improve donation and transplant.

- Discuss challenges that OPOs face and potential solutions for overcoming those barriers.

Moderator: SUE DUNN, *Committee Member*

Panelists:

JOE FERREIRA
President, Association of Organ Procurement Organizations
CEO, Nevada Donor Network

ALEXANDRA GLAZIER
CEO
New England Donor Services

DIANE BROCKMEIER
President and CEO
Mid-America Transplant

12:20 p.m. **Discussion with Committee** (15 mins)

12:35 p.m. **Break** (15 mins)

SESSION III. TRANSPLANT CENTER OPERATIONS AND ORGAN ACCEPTANCE DECISIONS

Session Chair: LEIGH ANNE DAGEFORDE, *Committee Member*

Session Objective: Discuss the opportunities and challenges facing transplant centers, and explore what is working and not working in terms of accessing organs, considering organ offers, managing waitlists, and optimizing the use of available organs.

12:50 p.m. **A Moderated Discussion on the Challenges and Opportunities for Improving Organ Use at the Transplant Center Level**

Moderator: LEIGH ANNE DAGEFORDE, *Committee member*

Panelists (5 minutes of remarks each):

RICHARD HASZ
Vice President, Clinical Services
Gift of Life Donor Program, Philadelphia

ALEXANDRE LOUPY
Professor of Nephrology and Epidemiology
Paris University

SUMIT MOHAN
Associate Professor of Epidemiology and Medicine
Columbia University Medical Center

BRIGITTE SULLIVAN
Executive Director
NYU Langone Transplant Institute

KELLY WATSON
Transplant Coordinator, Lung Transplant
University of North Carolina

1:45 p.m. **Discussion with Committee** (20 mins)

SESSION IV. DATA COLLECTION AND MODELING

Session Chair: DORRY SEGEV, *Committee Member*

Session Objective: Examine the current approach to modeling proposed organ allocation policy changes (e.g., simulated allocation models – SAMs), including successes and limitations, and consider new opportunities for improving organ allocation models.

Moderator: DORRY SEGEV, *Committee member*

2:05 p.m. **The Role of Modeling in Proposed Organ Allocation Policy Changes**

DAVID MULLIGAN
President, Organ Procurement and Transplantation Network/United Network for
Organ Sharing
Professor of Surgery (Transplant); Section Chief, Transplantation Surgery and
Immunology
Yale University

2:15 p.m. **Simulated Allocation Models (SAMs) and Their Strengths and Limitations Including Data Availability**

JON SNYDER
Director
Scientific Registry of Transplant Recipients (SRTR)

2:25 p.m. **Envisioning the Future – Opportunities for Improving Organ Allocation Models**

NIKHIL AGARWAL
Associate Professor, Economics
MIT

2:35 p.m. **How Well Do Organ Allocation Policies Correlate to Models – A Case Study**

MICHAEL GIVERTZ
Medical Director, Heart Transplant and Mechanical Circulatory Support
Brigham and Women's Hospital; Harvard University

2:45 p.m. **Discussion with Committee** (15 mins)

3:00 p.m. **Break** (10 mins)

SESSION V. PUBLIC COMMENT PERIOD

Moderator: KENNETH W. KIZER, *Committee Chair*

3:10 p.m. **Receive comments from individuals registered in advance (2 minutes each)**

3:55 p.m. **Reflections on Day 1 and Preview of Day 2**

KENNETH W. KIZER, *Committee Chair*
Chief Healthcare Transformation Officer
Senior Executive Vice President
Atlas Research

4:00 p.m. **Adjourn Workshop Day 1**

DAY 2: Friday, February 5, 2021

10:00 a.m. **Welcome and Overview of Day 2**

KENNETH W. KIZER, *Committee Chair*
Chief Healthcare Transformation Officer
Senior Executive Vice President
Atlas Research

SESSION VI. EXPLORING DISPARITIES AND ACCESS ISSUES IN ORGAN PROCUREMENT, ALLOCATION, AND DISTRIBUTION

Session Chair: JEWEL MULLEN, *Committee Member*

Session Objectives:

- Explore what is known about inequities and disparities in deceased donor organ procurement, allocation, and distribution.
- Discuss which communities are affected and examine the impact of disparities on those communities.
- Learn about successful efforts to mitigate these disparities/inequities.

Moderator: JEWEL MULLEN, *Committee Member*

10:10 a.m. **Inequities and Disparities in Deceased Donor Organ Procurement, Allocation, and Distribution**

KIMBERLY JACOB ARRIOLA
Professor, Rollins School of Public Health
Emory University

10:25 a.m. **The Role of Communication Dynamics in Organ Procurement, Allocation, and Distribution**

LAURA SIMINOFF
Dean, College of Public Health
Temple University

10:40 a.m. **Panel Discussion – Perspectives on Disparities and Access Issues**

Moderator: ELISA GORDON, *Committee Member*

Panelists (5 minutes of remarks each):

MARYAM VALAPOUR
Senior Staff for Lung Transplantation
Scientific Registry of Transplant Recipients (SRTR)
Staff, Respiratory Institute, Cleveland Clinic

BURNETT “BEAU” KELLY
Surgical Director
Dialysis Clinic Inc. Donor Services

LILIA CERVANTES
Associate Professor of Medicine
University of Colorado

AARON WIGHTMAN
Pediatric Nephrologist and Bioethicist
University of Washington

KEREN LADIN
Associate Professor, Public Health and Community
Tufts University

11:20 a.m. **Discussion with Committee** (30 mins)

11:50 a.m. **Break** (20 mins)

SESSION VII. DECEASED DONOR FAMILY PERSPECTIVES

Session Chair: CHARLES BEARDEN, *Committee Member*

Session Objective: Receive the perspectives of family members of deceased organ donors.

12:10 p.m. **Panel Discussion: Perspectives from the Family Members of Organ Donors**

Moderator: CHARLES BEARDEN, *Committee Member*

Panelists:

GABRIELA LANDEROS-WILLIAMS
Donor Family Member

DEANNA SANTANA
Donor Family Member

KENNETH MORITSUGU
Donor Family Member

12:40 p.m. **Discussion with Committee** (20 mins)

1:00 p.m. **Break** (10 mins)

SESSION VIII. TRANSPLANT RECIPIENT PERSPECTIVES

Session Chair: KENNETH KIZER, *Committee Chair*

Session Objectives: Receive the perspectives of individuals who have received a donor organ, and explore the factors that played into their decision making process.

1:10 p.m. **Moderated Panel Discussion with Donor Organ Recipients**

Moderator: KENNETH W. KIZER, *Committee Chair*

Panelists:

ALEXIS CONELL
Member, Community Advisory Council
APOLLO Research Study

HALA DURRAH
Patient Family Engagement Consultant and
Advocate, and Parent of a Liver Transplant Recipient.

RICHARD KNIGHT
President
American Association of Kidney Patients
Transplant Recipient

ROBERT MONTGOMERY
Chair, Department of Surgery
NYU Langone Transplant Institute

1:40 p.m. **Discussion with Committee** (20 mins)

SESSION IX. COSTS AND OTHER ECONOMIC FACTORS

Session Chair: DENNIS WAGNER, *Committee Member*

Session Objectives: Consider the economic costs of the organ procurement, allocation, and distribution systems, and determine who is paying those costs and if there are opportunities to compress costs.

2:00 p.m. **Moderated Panel Discussion with Select Speakers**

Moderator: DENNIS WAGNER, *Committee Member*

MARK SCHNITZLER (7 mins)

Director of Outcomes Research and Quality for Transplantation
Saint Louis University

DAVID AXELROD (7 mins)

Professor, Kidney, Pancreas, and Living Donor Transplantation Surgical
Director, Fellowship Director, Transplant
University of Iowa

Synthesis & Reaction: MARIO MACIS, *Committee Member*

CHARLES ROSEN (7 mins)

Professor of Surgery, Division of Transplantation Surgery
Medical Director, Department of Contracting and Payer Relations
Mayo Clinic

SARA EVE SHAEFFER (1 min)

Executive Director, ESRD NCC
Health Services Advisory Group, Inc.

CHRISTOPHER ZINNER (6 mins)

Managing Director
Accenture Federal Services

Synthesis & Reaction: NEIL POWE, *Committee Member*

2:35 p.m. **Discussion with the Committee** (15 mins)

2:50 p.m. **Reflections on Day 2**

KENNETH W. KIZER, *Committee Chair*

3:00 p.m. **Adjourn Workshop**

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HEALTH AND MEDICINE DIVISION
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and Transparent System of Donor Organ Procurement, Allocation,
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TAB II
Statement of Task
Committee Roster
Committee and Staff Biosketches

A Fairer and More Equitable Cost-Effective and Transparent System of Donor Organ Procurement, Allocation, and Distribution

Statement of Task

An ad hoc committee of the National Academies of Sciences, Engineering, and Medicine will conduct a consensus study to examine the economic (costs), ethical, policy, regulatory, and operational issues relevant to organ allocation policy decisions involving deceased donor organs (e.g., heart, lung, liver, kidney, kidney-pancreas, intestinal, vascular composite allografts, dual and/or multi-organ organ transplants). The committee will examine the gaps, barriers, and opportunities for improving deceased donor organ procurement, allocation, and organ distribution to waiting recipients at transplant centers with a keen eye towards optimizing the quality and quantity of donated organs available for transplantation – in a cost effective and efficient, fair and equitable manner consistent with the National Organ Transplant Act and the Final Rule.

Specifically, the final consensus report will delineate the issues pertinent to organ allocation policy, modelling and simulation of anticipated policy changes for intended and unintended consequences, and the process for efficiently executing allocation policy changes in an open, transparent, fair, and equitable manner. The report will make recommendations to maximize public and professional trust in the organ donation, procurement, allocation, and distribution process. The report will also make recommendations to better align the performance metrics or incentives of various stakeholders within the Organ Procurement and Transplantation Network [specifically donor service areas (DSAs), organ procurement organizations (OPOs), and transplant centers] to maximize donor referrals, evaluations, procurement and organ placement/allocation while minimizing organ discard rates.

The committee will consider the following in its discussions and deliberations to address the statement of task:

- If deceased donor organs should be allocated to specific individuals based on need (i.e., national, continuous framework) rather than groups of individuals defined by locale, zip code, or donor service area (i.e., the donor service area, geographic framework) and if measures can be taken to reduce inequities in organ allocation affecting socioeconomically disadvantaged populations;
- Relevant factors that determine transplant recipient waitlist priority (i.e., “need”) for an organ;
- Best model/method(s) to ensure fairness, equity, cost effectiveness and efficiency, and reduce the reported socioeconomic and racial/ethnic disparities in the current organ allocation system;
- Challenges with current organ allocation policy development and policy change procedures and processes, including opportunities to update OPTN policies and processes to ensure organ allocation decisions consider the viewpoints of expert OPTN committees;
- Challenges involved in modeling proposed organ allocation policy changes and opportunities to improve modeling, including how costs should be factored into the modeling of organ allocation policy changes;
- Appropriate parameters, factors, and variables that should make up various transplant scoring

systems (e.g., CPRA, EPTS, KDPI, LAS, MELD, etc.) that determine organ allocation and patient prioritization to assure fair and equitable practices and reduce inequalities affecting socioeconomically disadvantaged patient populations;

- How to more effectively acquire needed data points to enhance transplant scoring systems (e.g., through better sharing of donor and recipient data between various federal agency databases);
- Self-reported donation metrics (e.g., “eligible deaths”) and the impact on estimates of the true donor supply. Consider the development of a new, standardized, objective, and verifiable donation metric to permit the transplant community to evaluate DSAs and OPOs and establish best practices;
- Data sharing and optimization opportunities, revealed by the COVID-19 pandemic, via collaboration across Department of Health and Human Services administrative databases regarding vital statistics on transplant recipients and potential donors to better inform policy makers, the OPTN, OPOs, transplant centers, transplant healthcare workers, patients, and the public; and
- Relevant comparisons to international allocation policies and models.

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**Committee on a Fairer and More Equitable, Cost-Effective, and Transparent System of
Donor Organ Procurement, Allocation, and Distribution**

COMMITTEE ROSTER

Kenneth W. Kizer, MD, MPH (Chair)

Chief Healthcare Transformation Officer and
Senior Executive Vice President
Atlas Research

Itai Ashlagi, PhD

Associate Professor
Stanford University

Charles Bearden, PA, CPTC

Senior Organ Transplant Coordinator
Clinical Consulting Associates

Yolanda T. Becker, MD, FACS, FAST

Professor of Surgery
University of Chicago

Alexander M. Capron, LLB

Professor, Gould School of Law
University of Southern California

Bernice Coleman, PhD, ACNP-BC, FAHA, FAAN

Director, Nursing Research Department
Cedars-Sinai

Leigh Anne Dageforde, MD, MPH

Transplant Surgeon and Asst. Professor
Massachusetts General Hospital
Harvard Medical School

Sue Dunn, RN, MBA

Chief Executive Officer (Retired)
Donor Alliance

Robert Gibbons, PhD

Blum-Riese Professor of Biostatistics
The University of Chicago

Elisa Gordon, PhD, MPH

Professor, Dept. of Surgery
Feinberg School of Medicine
Center for Health Services and
Outcomes Research
Northwestern University

Renée Landers, JD

Professor and Director, Health Law
Faculty Director, Law Life Sciences
Suffolk University

Mario Macis, PhD

Professor, Carey Business School
Johns Hopkins University

Jewel Mullen, MD, MPH, MPA

Associate Dean for Health Equity
University of Texas at Austin,
Dell Medical School

Neil R. Powe, MD, MPH, MBA

Chief of Medicine, Zuckerberg San Francisco General Hospital, and Professor of Medicine University of California, San Francisco

Dorry Segev, MD, PhD

Marjory K. and Thomas Pozefsky Professor of Surgery and Epidemiology Johns Hopkins University

Dennis Wagner, MPA

Chief Executive Officer
Yes And Leadership, LLC

James Young, MD

Executive Director of Academic Affairs, Cleveland Clinic; Professor of Medicine & Vice- Dean for Academic Affairs, Cleveland Clinic Lerner College of Medicine of Case Western Reserve University George & Linda Kaufman Chair, Heart & Vascular Institute

STAFF CONTACTS

Rebecca English, MPH

Study Director
Email: renglish@nas.edu

Siobhan Addie, PhD

Program Officer
Email: saddie@nas.edu

Meredith Hackmann

Associate Program Officer
Email: mhackmann@nas.edu

Kendall Logan

Senior Program Assistant
Email: klogan@nas.edu

Liz Townsend, MPH

Associate Program Officer
Email: etownsend@nas.edu

Andrew M. Pope, PhD

Senior Board Director
Health Sciences Policy
Email: apope@nas.edu

Sharyl Nass, PhD

Senior Board Director
Health Care Services
Email: snass@nas.edu

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BOARD ON HEALTH SCIENCES POLICY**

**Committee on a Fairer and More Equitable, Cost-Effective, and Transparent System of
Donor Organ Procurement, Allocation, and Distribution**

COMMITTEE AND STAFF BIOSKETCHES

COMMITTEE MEMBERS

Kenneth W. Kizer, M.D., M.P.H., (NAM) (*Chair*) currently serves as the Chief Health Care Transformation Officer and Senior Executive Vice President for Atlas Research. He has been elected to both the National Academy of Medicine and the National Academy of Public Administration. Dr. Kizer is a highly experienced physician executive whose diverse professional experience includes senior leadership positions in the public and private sectors, academia, and philanthropy. He has previously served as founding President and CEO, National Quality Forum; Under Secretary for Health, U.S. Department of Veterans Affairs, and chief executive officer of the nation's largest healthcare system, during which time he engineered the internationally acclaimed transformation of the Veterans Healthcare System in the late 1990s; founding Chairman, President and CEO, Medsphere Systems Corporation, a leading commercial provider of subscription-based health information technology; founding Director, Institute for Population Health Improvement and Distinguished Professor, University of California, Davis; inaugural Chief Medical Officer, California Department of Managed Health Care; Director, California Department of Health Services; and Director, California Emergency Medical Services Authority, where he was the architect of the state's EMS and trauma care systems in the early 1980s. During his record tenure as California's top health official he won high praise for orchestrating the state's response to the then new HIV/AIDS epidemic, implementing California's famed Tobacco Control Program and the '5-a-Day' for Better Nutrition Program that was later adopted for national implementation, pioneering Medicaid managed care, and restructuring many of the state's public health programs. He also has served on the U.S. Preventive Services Task Force and as Chairman of The California Wellness Foundation. Dr. Kizer has longstanding interests in organ transplantation stemming from his experience as a practicing emergency physician, public health official, and health system leader, as well as his personal experiences as the husband of a multiple times organ transplant recipient. He has a deep understanding of the anxieties and difficulties families experience while waiting for an organ.

Itai Ashlagi, Ph.D. is an Associate Professor at the Management Science and Engineering Department at Stanford University. Dr. Ashlagi's research interests include game theory and the design and analysis of marketplaces. He specializes in matching markets, such as kidney paired donation, organ allocation, school choice, and the National Resident Matching Program. Dr. Ashlagi is a recipient of the National Science Foundation (NSF) CAREER award and is recognized as a Franz Edelman Laureate for his outstanding contributions to kidney paired donation. Before joining Stanford University, he was an assistant professor of Operations Management at the Massachusetts Institute of Technology's Sloan School of Management and, prior to that, a postdoctoral researcher at Harvard Business School. Dr. Ashlagi received his Ph.D. in Operations Research from the Technion-Israel Institute of Technology.

Charles Bearden, P.A., C.P.T.C. has been a practicing PA for over 48 years. He has the distinction of being the longest practicing organ recovery/transplant coordinator in the United States with 44 years of coordinating over 2500 heart, lung, liver, kidney, pancreas, and intestinal organ transplants. Mr. Bearden is currently the Senior Organ Transplant Coordinator for Clinical Consulting Associates. Prior to beginning his Physician Associate studies, Mr. Bearden worked as a Cardiovascular Technician at Grady Memorial Hospital in Atlanta, GA and trained under Dr. J. Willis Hurst. Dr. Hurst was starting the PA Program at Emory and encouraged him to apply to the first Physician Associate Program class at the Emory University School of Medicine in 1971. He was accepted and at the age of 19 began his PA education. He served as class vice president and graduated in 1973. He made the highest score in his class on the first National Board of Medical Examiners (NBME) Certifying Examination for PAs held in 1973. In 1974, Mr. Bearden served on the NBME Committee to validate the first PA National Board Examination. He was NCCPA certified in both Primary Care (1975) and Surgery (1980). In 1978 he co-founded and co-directed the first Organ Bank in Atlanta and remained with the Atlanta branch of DCI until 1988 when he relocated to their Chattanooga, TN, office. Mr. Bearden remained with DCI Donor Services until 2002 when he accepted a position as a Traveling Organ Recovery Coordinator with Clinical Consulting Associates (CCA). In 2007, Mr. Bearden became one of the first Virtual Organ Transplant Coordinators in the country for CCA and he continues his work today. He has been certified by the American Board of Transplant Coordination for 34 years. He is a member of the Advisory Board of Organize.org and was a participant in the 2016 White House Summit on Organ Donation and Transplantation.

Yolanda T. Becker, M.D. (FACS, FAST) is a professor of surgery and director of kidney and pancreas transplantation at the University of Chicago. She has served in many roles throughout her career as a Transplant Surgeon. Dr. Becker is a Past President of the OPTN/UNOS (Organ Procurement and Transplant Network/United Network for Organ Sharing) board of directors. She has served on the UNOS corporate affairs committee, the nominating committee and the board governance subcommittee. She has chaired the policy oversight committee. Dr. Becker began her involvement with UNOS as a member of the MPSC (Membership and Professional standards committee), and certification maintenance workgroups, co-chairing the latter. Dr.

Becker has served as an elected member of the American Society of Transplantation (AST) board of directors, co-chairing its winter symposium, chairing its education committee and additionally serving on the minority affairs committee. She has served on the American Society of Transplant Surgeons (ASTS) scientific studies committee and on the AST/ASTS American Transplant Congress program planning committee. She also has served on the board of directors of the National Kidney Registry. She earned her medical degree at the Johns Hopkins School of Medicine in Baltimore. Dr. Becker has received additional leadership training, completing the Executive Leaders in Academic Medicine program at Drexel University College of Medicine in Philadelphia.

Alexander M. Capron, LL.B. (NAM) is a University Professor at the University of Southern California where he teaches Public Health Law and Policy, Bioethics, and Torts, and occupies the Scott H. Bice Chair in Healthcare Law, Policy and Ethics in the Gould School of Law, is Professor of Medicine and Law in the Keck School of Medicine, and is Co-Director of the Pacific Center for Health Policy and Ethics. He previously taught at Georgetown University, the University of Pennsylvania, and Yale University. His ten books and hundreds of articles cover a wide range of topics in law, medicine, and ethics; he has written on human organ transplantation since 1972, including, with Jay Katz, *Catastrophic Diseases: Who Decides What* (1975, paperback 1978). Capron received a BA from Swarthmore College and an LLB from Yale University, where he was an officer of the Yale Law Journal. He was appointed by Congress as the chair of the Biomedical Ethics Advisory Committee, and by President Bill Clinton as a member of the National Bioethics Advisory Commission. From 1980 to 1983 he was the Executive Director of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which was established by Congress and appointed by Presidents Carter and Reagan; in one of its dozen reports, *Defining Death: The Medical, Legal and Ethical Issues in the Determination of Death* (1981), the commission set forth the Uniform Determination of Death Act which it had developed with three medical and legal organizations. From 2002-06, he served as Director of the Department of Ethics, Trade, Human Rights and Health Law at the World Health Organization, where he co-led its global work on human organ, tissue, and cell transplantation. He is an elected member of the National Academy of Medicine and the American Law Institute and an elected Fellow of the American Association for the Advancement of Science and of the Hastings Center. He has served as President of the American Society for Law, Medicine and Ethics and of the International Association of Bioethics.

Bernice Coleman, Ph.D., A.C.N.P.-B.C., F.A.H.A., F.A.A.N. is Director of the Nursing Research Department and Performance Improvement Department, Assistant Professor of Medicine and Biomedical Sciences, and a Nurse Practitioner for the Heart Transplantation and Mechanical Circulatory Support at the Cedars-Sinai Smidt Heart Institute. She is a member of AHA Leadership Council on Cardiovascular and Stroke Nursing, past chairperson of the Nursing Health Science and Allied Health Council of the International Society of Heart and Lung

Transplantation, and a member of the Nominating Committee for the International Society of Nurses in Genetics. Dr. Coleman was a member of the U.S. Department of Health and Human Services Advisory Committee on Organ Transplantation. She researches health disparities with a focus on exploring the racial outcomes of post-heart transplantation African and Caucasian Americans. Dr. Coleman is a board-certified Acute Care Nurse Practitioner with a Master of Science in Nursing from the Yale School of Nursing and a PhD from the UCLA School of Nursing. She has completed postdoctoral studies in the HLA Laboratory at Cedars-Sinai and the NINR Summer Genetics Institute. She is a fellow of the American Academy of Nursing and has presented her work in heart transplantation nationally and internationally.

Leigh Anne Dageforde, M.D., M.P.H. is an abdominal organ transplant (liver, kidney, and pancreas) and hepatobiliary surgeon at Massachusetts General Hospital who specializes in the care of patients with end stage kidney and liver disease needing organ transplantation, living kidney donors, pancreas transplant patients, and patients with liver and biliary cancer. Dr. Dageforde attended medical school at Vanderbilt University School of Medicine and completed her general surgery residency at Vanderbilt University Medical Center in Nashville, Tennessee. She completed her fellowship in Abdominal Organ Transplantation and HPB surgery at Washington University in St. Louis. In addition to liver, kidney and pancreas transplantation, her clinical interests also include living kidney donation and treatment of liver and biliary cancer. Dr. Dageforde completed her Master of Public Health degree at Vanderbilt University School of Medicine with a focus on research in improving access to transplantation. She serves on national committees in both the Association of Academic Surgery and the Americas Hepato-Pancreato-Biliary Association. Most recently she was appointed as the co-chair of the American Society of Transplant Surgeons Pipeline Taskforce focusing on the development of the rising surgical workforce in transplant surgery with an emphasis on mentorship of medical students and residents.

Sue Dunn, R.N., M.B.A. is the former chief executive officer of Donor Alliance. She led the Denver-based organ procurement organization (OPO) serving Colorado and Wyoming for more than 15 years. Ms. Dunn joined Donor Alliance in 1989. She served as the organization's vice president of Organ Procurement Operations/Compliance and Regulatory Affairs before being named CEO in 2004. Prior to Donor Alliance, Ms. Dunn spent five years as an organ procurement coordinator in Minnesota. She also served as OPTN and UNOS board president from 2018-2019, leading semiannual meetings of the board, as well as chairing the Executive Committee and UNOS' Corporate Affairs Committee. She is formerly the president of the Association of Organ Procurement Organizations (AOPO) and has served on numerous industry boards and committees. Under Ms. Dunn's leadership, Donor Alliance was recognized as a 2018 Malcolm Baldrige National Quality Awardee, the only non-profit organization that year, and the second organ procurement organization to be recognized. She has earned widespread recognition for her leadership at Donor Alliance.

Robert D. Gibbons, Ph.D. (NAM) is the Blum-Riese Professor of Biostatistics and a Pritzker Scholar at the University of Chicago. He has appointments in the Departments of Medicine, Public Health Sciences and Comparative Human Development. He also directs the Center for Health Statistics. Dr. Gibbons is a Fellow of the American Statistical Association, the International Statistical Institute, and the Royal Statistical Society, and a member of the National Academy of Medicine of the National Academy of Sciences. He has authored more than 300 peer-reviewed scientific papers and six books. His statistical work spans the areas of longitudinal data analysis, item response theory, environmental statistics and drug safety and has led to thousands of applications in the biological and social sciences. Dr. Gibbons has received lifetime achievement awards from the American Statistical Association, the American Public Health Association and Harvard University. He is a founder of the Mental Health Statistics section of the American Statistical Association. Dr. Gibbons has coauthored many publications, including “Full-Information Item Bi-Factor Analysis,” “Waiting for Organ Transplantation,” and “Weighted Random-Effects Regression Models with Application to Inter-Laboratory Calibration.” He earned his Ph.D. in statistics and psychometrics from the University of Chicago and his B.A. in chemistry and mathematics from the University of Denver.

Elisa J. Gordon, Ph.D., M.P.H. is Professor in the Department of Surgery-Division of Transplantation, Center for Health Services and Outcomes Research, and Center for Bioethics & Medical Humanities at Northwestern University Feinberg School of Medicine. Dr. Gordon completed her doctorate in Medical Anthropology at Case Western Reserve University. Thereafter, she completed a Fellowship in Clinical Medical Ethics at the University of Chicago. Dr. Gordon obtained her Master’s degree in Public Health from the University of Illinois, Chicago, specializing in Community Health Sciences. Her research interests include: ethics of organ transplantation and donation, health disparities in access to health care and health outcomes, developing interventions to enhance patients' informed consent and treatment decision making, and qualitative research and mixed-methods. Dr. Gordon has received funding from the NIH, HRSA, VA, and DOD for her research in transplantation and decision aids.

Renée Landers, J.D. is a Professor of Law, Faculty Director of the Health and Biomedical Law Concentration, and Faculty Director of the Masters of Science in Law Life Sciences program at Suffolk University Law School in Boston. She was a Distinguished Visiting Fellow at the National Academy of Social Insurance during her fall 2018 sabbatical leave. She was also the President of the Boston Bar Association in 2003-2004, and was the first woman of color and the first law professor to serve in that position. Professor Landers has worked in private practice and served as Deputy General Counsel for the U.S. Department of Health and Human Services and as Deputy Assistant Attorney General in the Office of Policy Development at the U.S. Department of Justice during the Clinton Administration. Professor Landers served as Chair of the Section of Administrative Law and Regulatory Practice of the American Bar Association in 2016 – 2017 and chaired the Section’s Nominating Committee in 2018 - 2019. She is a Trustee of the Massachusetts General Hospital and a former Trustee of New England Donor Services and

the Massachusetts Eye & Ear Infirmary. In 2019, she rejoined the board of Planned Parenthood League of Massachusetts and became President of the Board beginning in July 2020. Recently, she co-chaired the Boston Bar Association's Task Force on Judicial Independence which issued a report in August 2019. She was a member of the Massachusetts Commission on Judicial Conduct and served as Vice Chair of the Commission from 2009 to 2010. She also served on the task force that drafted the revised Massachusetts Code of Judicial Conduct effective in 2016 and currently is a member of the Committee on Judicial Ethics which advises judges on compliance with the Code. Previously, she was a member of the Supreme Judicial Court's committees studying gender bias and racial and ethnic bias in the courts.

Mario Macis, Ph.D. is a Professor of Economics at the Johns Hopkins University Carey Business School. He is also a Core Faculty member of the Hopkins Business of Health Initiative, Affiliate Faculty at the Johns Hopkins Berman Institute of Bioethics, and Faculty Research Fellow at the National Bureau of Economic Research. Dr. Macis is an applied economist and his work focuses on how economic incentives interact with psychological factors and social norms to drive individual behavior and policy-relevant outcomes. His main research interests are in prosocial behavior, ethics and economics, and experimental economics. Much of his recent research involved multi-disciplinary collaborations with medical and public health scholars and psychologists. He regularly engages with policy makers and practitioners, including national and international agencies as well as associations related to blood, plasma, stem cell, and organ donation. In particular, he conducted studies in partnership with the American Red Cross and the National Marrow Donor Program. His work was published in leading academic journals including the American Economic Review, Management Science, the Journal of Health Economics, and the American Economic Journal: Economic Policy, and Science. Dr. Macis has been a consultant for the World Bank, the International Labor Organization, the National Marrow Donor Program, and the United Nations Development Program.

Jewel Mullen, M.D., M.P.H., M.P.A. is Associate Dean for Health Equity at University of Texas at Austin Dell Medical School, as well as an associate professor in the school's population health and internal medicine departments. She also serves as Director of Health Equity at Ascension Seton to help meet health equity goals across its system. Mullen is an internist, epidemiologist, public health expert and the former principal deputy assistant secretary for health in the U.S. Department of Health and Human Services (HHS). While at HHS, she also served as the acting assistant secretary for health and acting director of the National Vaccine Program Office. Prior to HHS, she served as commissioner of the Connecticut Department of Public Health. Her career has spanned clinical, research, teaching and administrative roles focused on improving the health of all people, especially those who are underserved. She is recognized nationally and internationally as a leader in building effective community-based chronic disease prevention programs and for her commitment to improving individual and population health by strengthening coordination between community, public health and health care systems. A former President of the Association of State and Territorial Health Officials, Dr. Mullen is a current

member of the Center for Disease Control and Prevention's Morbidity and Mortality Weekly Report Editorial Board, the ChangeLab Solutions Board of Directors, and the Robert Wood Johnson Foundation's Policies for Action National Advisory Committee which she chairs. She also is a member of the Study Committee on the Equitable Allocation of COVID-19 Vaccine at the National Academies of Science, Engineering and Medicine; and a former member of the Advisory Committee to the CDC Director and its subcommittee on health disparities. Dr. Mullen received her bachelor's and Master of Public Health degrees from Yale University where she also completed a post-doctoral fellowship in psychosocial epidemiology. She graduated from the Mount Sinai School of Medicine, and completed her residency at the Hospital of the University of Pennsylvania. She also holds a Master of Public Administration from Harvard University's John F. Kennedy School of Government and completed intensive and advanced bioethics courses at the Kennedy Institute of Ethics.

Neil R. Powe, M.D., M.P.H., M.B.A. (NAM) serves as leader of the University of California San Francisco Medicine Service at the Priscilla Chan and Mark Zuckerberg San Francisco General Hospital, a leading Medicine department in a public hospital with strong basic, clinical and health services research programs focused on major diseases affecting diverse patients locally, nationally and globally. His interests are in improving discovery, education, clinical practice and organizational effectiveness in medicine, enhancing scholarship and multidisciplinary collaboration, and developing future talent and leadership in the health professions. He has a particular interest in cultivating young scientists who are addressing major problems in science, health and health care delivery. His primary intellectual pursuits involve kidney disease patient-oriented research, epidemiology, disparities, and outcomes and effectiveness research. His research unites Medicine and Public Health and involves the knowledge of fundamental discoveries in biology and clinical medicine to advance the health of patients and populations. He has conducted research on disparities in organ donation and interventions to improve access to kidney transplantation. Dr. Powe is a member of the National Academy of Medicine, Master of the American College of Physicians and Fellow in the American Association for the Advancement of Science. Among his honors are the John M. Eisenberg Award for Career Achievement in Research from the Society of General Internal Medicine, the Belding Scribner Award from the American Society of Nephrology, the David Hume Memorial Award from the National Kidney Foundation and the John Phillips Memorial Award for Distinguished Contributions in Clinical Medicine from the American College of Physicians. Dr. Powe earned his medical degree at Harvard Medical School and his master's in public health at Harvard School of Public Health. He completed residency, was a Robert Wood Johnson Clinical Scholar and completed his master's in business administration at the University of Pennsylvania.

Dorry Segev, M.D., Ph.D. (NAM) 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),

the largest and most prolific group of its kind in the world. 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. With a graduate degree in biostatistics, Dr. Segev focuses on novel statistical and mathematical methods for simulation of medical data, analysis of large healthcare datasets, and outcomes research.

Dennis Wagner, M.P.A. is CEO of Yes And Leadership, LLC, and former director of the iQuality Improvement and Innovation Group in the CMS Center for Clinical Standards and Quality. Dennis and his team supported healthcare providers who are using systematic quality improvement to make care better in tens of thousands of hospitals, nursing homes, clinical practices and communities across the nation. This team of public and private quality improvers actively work to spread the best practices of highest performers, so that “best practices become common practice.” Prior to his most recent role at CMS, Dennis served as the Associate Director for Campaign Leadership in the Centers for Medicare and Medicaid Innovation (CMMI), and as Deputy Director and then Acting Director of the CMS Office of Clinical Standards and Quality. Prior to his departure in March of 2020, Dennis was successful in supporting cross-Departmental work to develop and announce a major national Departmental & Presidential Kidney Health Initiative, which included CMS Innovation Center initiatives to support, increased kidney procurement and utilization. While at HRSA’s Division of Transplantation, Dennis led a series of major national initiatives, including the Organ Donation Breakthrough Collaborative, from 2003-2007 to increase the donation and transplantation of organs. This work generated unprecedented and lasting national increases in organ donation over this four-year period. In addition to numerous honors and awards from CMS, HHS, HRSA and EPA, Dennis is a recipient of the Samuel J. Heyman Service to America Medal (known as the “Sammies”) 2016 Federal Employee of the Year Award. Dennis received his B.A. and M.P.A. degrees from Montana State University.

James B. Young, M.D. is Cleveland Clinic’s Executive Director of Academic Affairs and Academic Vice-Dean, Cleveland Clinic Lerner College of Medicine of Case Western Reserve University. He also holds the George and Linda Kaufman Chair in the Heart and Vascular Institute. He was the Medical Director of the Kaufman Center for Heart Failure, which he and a former surgical colleague established in 1998 at Cleveland Clinic. After joining Cleveland Clinic in 1995, Dr. Young was named Head of Heart Failure and Cardiac Transplant Medicine. He is an internationally recognized heart failure and heart transplant cardiologist with an interest in mechanical circulatory support devices. Dr. Young has participated in more than 150 clinical trials as an investigator and has served as the U.S. principal or co-principal investigator for many multicenter clinical trials. He has published more than 700 manuscripts and several textbooks. A member of many professional associations, Dr. Young served as a board member and past

president of the International Society of Heart and Lung Transplantation, and as a board member of the Heart Failure Society of America and the American Society of Transplantation. Dr. Young earned a BA with honors in biology from the University of Kansas, where he was a resident of Stephenson Scholarship Hall. He matriculated to Baylor College of Medicine in Houston, where he was awarded his medical degree, cum laude, and was elected to the Alpha Omega Alpha medical honor society. He completed his clinical training at Baylor Affiliated Hospitals. Dr. Young is a Fellow of the American College of Cardiology, American College of Physicians, American Heart Association and the European Society of Cardiology. He is a Diplomat of the American Board of Internal Medicine and the sub-specialty Boards of Cardiovascular Disease and Advanced Heart Failure and Cardiac Transplantation.

STAFF

Rebecca English, M.P.H., is a Senior Program Officer in the Board on Health Science Policy. She has directed, co-directed, and staffed a number of projects at the National Academies including, most recently: Necessity, Use, and Care of Laboratory Dogs at the U.S. Department of Veterans Affairs (2020); Temporomandibular Disorders: From Research Discoveries to Clinical Treatment (2020); Physician-Assisted Death: Scanning the Landscape (Proceedings of a Workshop; 2018); and Mitochondrial Replacement Techniques: Ethical, Social, and Policy Considerations (2016). She has also staffed the Forum on Drug Discovery, Development, and Translation in various capacities since 2009 and worked on wide ranging projects related to the U.S. clinical trials enterprise as well as multidrug-resistant tuberculosis throughout the world. Prior to joining the National Academies, she worked on health policy for Congressman Porter J. Goss (FL-14) and then for the National Active and Retired Federal Employees Association. Rebecca holds an M.P.H. from the University of Michigan, Ann Arbor, and a B.A. from the University of Notre Dame with a major in Political Science.

Siobhan Addie, Ph.D., is a Program Officer on the Board on Health Sciences Policy. Dr. Addie serves as a staff member on the Roundtable on Genomics and Precision Health and the Forum on Regenerative Medicine, two standing, convening activities at the National Academies. In her role at the Academies, she has developed public workshops and resulting publications on a wide range of topics including bioethics, drug discovery and development, implementation science, health disparities, and health care policy and economics. In addition, she oversaw the Genomics and Population Health action collaborative from 2016-2019, an ad hoc activity of the Genomics Roundtable. Prior to joining the staff of the National Academies, Dr. Addie was a Senior Program Manager in Life Sciences at the New York Academy of Sciences (NYAS). Before joining the staff at the NYAS, she was a postdoctoral researcher at Rockefeller University, where she used genetic and biochemical approaches to learn about a rare genetic disorder, Fanconi Anemia. Dr. Addie received her Ph.D. from the University of Pittsburgh, where her research explored the role of DNA repair enzyme ERCC1-XPF and how its absence can lead to cancer and aging. She earned her B.S. in Cell and Molecular Biology from the State University of New York at Binghamton in 2006.

Meredith Hackmann is an Associate Program Officer with the Roundtable on Genomics and Precision Health and the Forum on Regenerative Medicine under the Board on Health Sciences Policy at the National Academies of Sciences, Engineering, and Medicine. She joined the National Academies in 2014 and has helped facilitate public workshops, action collaboratives, and working groups in addition to providing background research and writing support for Roundtable publications and consensus studies within the Board on Health Sciences Policy. Prior to joining the Academies, she was an intern with the U.S. House of Representatives. She has volunteered with several nonprofit organizations on projects related to community health improvement in Central America, refugee and immigration issues, and

hospice care. Meredith earned a bachelor's degree in international studies from the University of Missouri.

Kendall Logan is a Senior Program Assistant for the Health and Medicine Division's Board on Health Sciences Policy. She joined the National Academies in 2018, and staffed two consensus studies: the Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults, and Temporomandibular Disorders (TMD): From Research Discoveries to Clinical Treatment. She also supports the standing committee on Medical and Epidemiological Aspects of Air Pollution on U.S. Government Employees and their Families. Kendall received her B.A. in Anthropology with a Public Health minor from Haverford College and is currently pursuing a Master of Public Health degree from Columbia University.

Liz Townsend, M.P.H., is an Associate Program Officer with the Board on Health Sciences Policy. Liz has worked on studies and workshops on topics in public health, social and behavioral sciences research, adolescent development, and economic policy. Recent projects include: The Clinical Utility of Compounded Bioidentical Hormone Therapy (2020); A Roadmap to Reducing Child Poverty (2019); The Promise of Adolescence (2019); and A Decadal Survey of the Social and Behavioral Sciences: A Research Agenda for Advancing Intelligence Analysis (2019). Prior to joining the National Academies, Liz managed a youth suicide prevention program for the State of Maine. She holds a B.S. from Radford University and an M.P.H. from the University of Alabama at Birmingham.

Andrew Pope, Ph.D., is Director of the Board on Health Sciences Policy. He has a Ph.D. in physiology and biochemistry from the University of Maryland and has been a member of The National Academies of Sciences, Engineering, and Medicine staff since 1982, and of the Health and Medicine Division staff since 1989. His primary interests are science policy, biomedical ethics, and environmental and occupational influences on human health. During his tenure at the Academies, Dr. Pope has directed numerous studies on topics that range from injury control, disability prevention, biologic markers to the protection of human subjects of research, National Institutes of Health priority-setting processes, organ procurement and transplantation policy, and the role of science and technology in countering terrorism. Since 1998, Dr. Pope has served as Director of the Board on Health Sciences Policy which oversees and guides a program of activities that is intended to encourage and sustain the continuous vigor of the basic biomedical and clinical research enterprises needed to ensure and improve the health and resilience of the public. Ongoing activities include Forums on Neuroscience, Genomics, Drug Discovery and Development, and Medical and Public Health Preparedness for Catastrophic Events. Dr. Pope is the recipient of the Health and Medicine Division's Cecil Award and the National Academy of Sciences President's Special Achievement Award.

Sharyl Nass, Ph.D. serves as Director of the Board on Health Care Services and Director of the National Cancer Policy Forum at the National Academies of Sciences, Engineering, and Medicine. The National Academies provide independent, objective analysis and advice to the nation to solve complex problems and inform public policy decisions related to science, technology, and medicine. To enable the best possible care for all patients, the Board undertakes scholarly analysis of the organization, financing, effectiveness, workforce, and delivery of health care, with emphasis on quality, cost, and accessibility. The Cancer Forum examines policy issues pertaining to the entire continuum of cancer research and care. For more than 2 decades, Dr. Nass has worked on a broad range of health and science policy topics that includes the quality and safety of health care and clinical trials, developing technologies for precision medicine, and strategies for large-scale biomedical science. She has a Ph.D. in cell biology from Georgetown University and undertook postdoctoral training at the Johns Hopkins University School of Medicine, as well as a research fellowship at the Max Planck Institute in Germany. She also holds a BS and an MS from the University of Wisconsin-Madison. She has been the recipient of the Cecil Medal for Excellence in Health Policy Research, a Distinguished Service Award from the National Academies, and the Institute of Medicine staff team achievement award (as team leader).

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HEALTH AND MEDICINE DIVISION
Board on Health Sciences Policy
Board on Health Care Services

**The Committee on A Fairer and More Equitable, Cost-Effective,
and Transparent System of Donor Organ Procurement, Allocation,
and Distribution: Public Workshop**

February 4 & 5, 2021

Virtual Public Workshop

**BRIEFING BOOK
TABLE OF CONTENTS**

TAB III

Speaker Bios

Session Questions

Bibliography of Speaker-Suggested Resources

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

HEALTH AND MEDICINE DIVISION
Board on Health Sciences Policy
Board on Health Care Services

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Speaker Biographies

Nikhil Agarwal, Ph.D., is the Castle Krob Career Development Assistant Professor of Economics at MIT, where he has been teaching since 2014. He completed his Ph.D. in Economics at Harvard University in 2013, and was a Postdoctoral Associate at the Cowles Foundation for Economics Research at Yale University. Agarwal specializes in the empirical study of matching markets. He has developed new approaches that have been applied to study labor markets, education markets, and organ allocation systems. His research has been funded by the National Science Foundation and the National Institutes of Health.

Kimberly Jacob Arriola, Ph.D., M.P.H., is the Charles Howard Candler Professor of Behavioral, Social, and Health Education Sciences in the Rollins School of Public Health (RSPH) of Emory University. After graduating from Spelman College in 1994, she earned an MA in 1996 and PhD in 1998 from Northeastern University, both in Social Psychology. She earned an MPH in Epidemiology in 2001 from RSPH. For the past 20 years, her work has focused on social and behavioral factors that impact the health of African Americans. She has led the development, implementation, and evaluation of culturally-sensitive interventions to improve public commitment to organ and tissue donation among African Americans as well as multi-level interventions that address racial disparities in access to renal transplantation. In addition, she conducts research to study the role of race-related stress in chronic kidney disease progression among African Americans. She has also co-lead national and state-level efforts to evaluate structural interventions designed to improve health equity. Aside from being a faculty member, she serves as Executive Associate Dean for Academic Affairs for RSPH. In this role she serves to steward the academic mission of the school. This includes ensuring the integrity of the curriculum, helping to lead the re-accreditation process, and supporting faculty professional development among other things.

David A. Axelrod, M.D., M.B.A., is currently Professor of Surgery at the University of Iowa. He serves as the Surgical Director of Kidney, Pancreas, and Living Donor Transplantation and fellowship director. He previously was Section Chief of Solid Organ Transplantation at

Dartmouth Hitchcock Medical Center from 2005-16. In addition, he was a member of the clinical staff at Massachusetts General Hospital and subsequently at Lahey Hospital. His clinical interests include the surgical management of end-stage kidney and liver disease including treatment of hepatocellular carcinoma and portal hypertension. In addition, he has expertise in minimally invasive hepatic surgery including liver resection and radio-frequency ablation. His research interests including surgical outcomes analysis including economic evaluation, Markov modeling, and statistical process control techniques. Previous investigations have examined the economic impact of MELD on liver transplantation, quality outcome monitoring in organ transplantation, steroid free immunosuppression in kidney and pancreas transplants, and geographic disparities in access to organ transplant. Dr. Axelrod attended Harvard College prior to completing an MD and MBA at Duke University. He trained in general surgery and surgical critical care at the University of Michigan, health services research and economic analysis in the Robert Wood Johnson Clinical Scholars Program, and in multi-organ transplantation during his fellowship at Northwestern University. Dr. Axelrod has been active at the United Network for Organ Sharing serving pancreas transplant committee chairman, associate counselor for Region 1, and a member of the Policy Oversight Committee. He was elected to the Board of Directors in 2016. He is also active in the American Society of Transplant Surgeons, serving as chairman of the Business Practice Committee and the Standards Committee. He developed and led the ASTS Leadership Development Program at Kellogg School of Business, which is now in its 8th year. Dr. Axelrod is also a founding partner in XynManagement (XM) which was recently purchased by CareDx. XM is a technology and services company serving transplant centers through the development of cloud based quality of care monitoring software and outsource patient management solutions. XM now provides services for more than 30 leading transplant programs and is launching a new product this spring to provide comprehensive QAPI documentation, analysis, and tracking.

Diane Brockmeier, M.A., is the President and CEO of Mid-America Transplant. As President and CEO, she oversees strategic operations, including key partnerships with more than 120 hospitals and transplant centers located throughout Missouri, northeast Arkansas and southern Illinois. She has been with the organization for over 34 years, first as a nurse and organ procurement coordinator and then rising through the ranks to becoming president and CEO in February 2016. Her key accomplishments include overseeing the design, construction and use of a first-in-the-nation, on-site surgical suite for organ and tissue recovery, which led to praise by donor hospitals and transplant surgeons for its enhanced quality control and convenience. To date, her leadership has overseen the largest industry experience in the utilization of free-standing Organ Recovery Centers (greater than 2,000 organ donors) with increasing donor management research efforts to drive improved outcomes while maintaining some of the lowest organ acquisition charges in the nation. Brockmeier was instrumental in quality and organizational changes that resulted in Mid-America Transplant being awarded the Malcolm Baldrige National Quality Award in 2016. Mid-America Transplant's journey with Baldrige led to lifesaving changes, more than doubling the number of organs transplanted from 300 in 2005 to 815 in 2020 and marked the first time an organ procurement organization has been named a Baldrige recipient. In 2018-2020, she initiated the creation of the first Endowed Chairs in Transplantation at both St. Louis academic medical centers to recognize leaders in lung and abdominal transplantation. Her oversight of the Mid-America Transplant Foundation has

resulted in the awarding of more than \$ 4.1 M dollars in donation & transplantation clinical research.

Lilia Cervantes, M.D., received her undergraduate degree at CU Boulder and completed both her medical degree and internal medicine residency at the University of Colorado School of Medicine. Her background as a first generation Latina inspired her deep commitment to becoming a physician as well as her community service, advocacy, and research focused on promoting social justice in medical education and care. Dr. Cervantes has worked for over 12 years as an internal medicine hospitalist at Denver Health, the safety-net hospital, and has dedicated her career to creating a healthcare workforce that is diverse as well as conducting research to improve person-centered and clinical outcomes among Latinx patients with chronic kidney disease. The catalyst for her interest in improving outcomes for Latinx patients with chronic kidney disease was a former undocumented Latina patient with kidney failure who struggled with emergency dialysis (dialysis in the emergency department when critically ill) and ultimately died. Funded by the RWJF and the Doris Duke Foundation, Dr. Cervantes discovered the worse outcomes of undocumented immigrants who rely only on emergency dialysis. In 2019, as a result of Dr. Cervantes' research and stakeholder engagement, Colorado Medicaid opted to include the diagnosis of kidney failure as a qualifying condition under Emergency Medicaid thereby expanding access to standard dialysis.

James Childress, Ph.D., has been University Professor, the John Allen Hollingsworth Professor of Ethics, Professor of Religious Studies, and Professor of Research in Medical Education at the University of Virginia, where he is now an emeritus professor. Dr. Childress also served as the Joseph P. Kennedy, Sr., Professor of Christian Ethics at the Kennedy Institute of Ethics at Georgetown University and a Visiting Professor at the University of Chicago Divinity School and Princeton University. In 1990, he was named Professor of the Year in the Commonwealth of Virginia by the Council for the Advancement and Support of Education, and in 2002 he received the University of Virginia's highest honor—the Thomas Jefferson Award. In spring 2010 he held the Maguire Chair in American History and Ethics at the Library of Congress. Dr. Childress is the author of numerous articles and several books in various areas of ethics, including (with Tom Beauchamp) *Principles of Biomedical Ethics*, now in its 8th edition and translated into several languages. Dr. Childress was vice chair of the national Task Force on Organ Transplantation, and he also served on the Board of Directors of the United Network for Organ Sharing (UNOS), the UNOS Ethics Committee, the Recombinant DNA Advisory Committee, the Human Gene Therapy Subcommittee, the Biomedical Ethics Advisory Committee, and several Data and Safety Monitoring Boards for NIH clinical trials. He was a member of the presidentially-appointed National Bioethics Advisory Commission (1996-2001). Dr. Childress is a member of the National Academy of Medicine and he has participated in and chaired several studies at the National Academies of Sciences, Engineering, and Medicine. His current research focuses on public bioethics, public health ethics, and just-war theory and practice. Dr. Childress received his BA from Guilford College, his BD from Yale Divinity School, and his MA and PhD from Yale University.

Alexis Conell is a kidney transplant recipient. In 2009, she was working full time, modeling, and going to school when her life changed in a way she never expected. She was diagnosed with Fibrillary Glomerulonephritis and was placed on the transplant list in Illinois. She didn't have the

option for a live donor, so she was waiting for a cadaver kidney. By the end of July 2011 after a round of chemotherapy, she was told she needed to begin Dialysis and was hospitalized to have a peritoneal dialysis catheter inserted. She did 9 hours of dialysis at home every night and then eventually had to add an exchange during workhours in her office. In April 2012 at the advice of her nephrologist she applied and was added to the transplant list in Madison, Wisconsin. She continued her dialysis treatment until she received the call she had been praying for on July 17, 2012. The University Wisconsin Hospital in Madison had a Kidney for her, and she was transplanted that evening. She is now seven years out and doing well. She occasionally has minor setbacks of illness due to the immunosuppression, but her kidney continues to do well. In 2019 she started "Alexis Conell Speaks". She speaks locally and travels sharing her story, experiences, and challenges. She discusses the importance of medication and lab consistency, wellness, fitness, and healthy food choices after transplant. It is so extremely important to get the word out especially in the African American community. She believes sometimes it's easier to hear information from people who have experienced the same things and even look like you. So far, she has been blessed to speak at seminars and expo's, in the media, gala's, meetings, hospitals and clinics, and for drug companies. Recently she has been partnering with fitness instructors and trainers, spin studios, and gyms to speak at their facilities to help get information out to their customers and it's going great. She strongly feels like this has been a missed opportunity. She is also studying to become a certified health coach as she only feels like this will put her in an even better position to help others. Alexis formerly served on the NKFI Associate Board and has participated in Springfield Lobby Day, NKFI Board meeting 2018, various health fairs, expos, and office volunteer. She also serves on the Community Advisory Board for the Apollo (APOL1) Study at the National Institutes of Health and was also recently interviewed in 2019 by Kaiser Health News regarding, "Medicare Anti-Rejection Medication Coverage After Kidney Transplant". She continues to share her story and her challenges to fight for change in hopes that others will have more positive experiences and are aware of their options during their journey.

Hala Durrah, M.T.A., is an independent patient family engagement consultant and nationally recognized advocate. Her passion for patient family engagement work stems from her experience as a mother of a chronically ill child who has undergone two liver transplants and a bone marrow transplant. As an expert in patient partnership and engagement, she serves as a consultant on a number of projects focused on patient centered measurement, quality improvement, patient safety, health equity, child health, healthcare transformation, health IT, patient partnered research, and patient experience. She serves on a number of national committees and boards, most recently being elected to American Board of Emergency Medicine as their first public member director. Ms. Durrah recently founded Patient Advocates Transforming Healthcare (PATH), a diverse coalition of independent patient, family, caregiver and community engagement leaders seeking to transform healthcare through our collective experiences and expertise. This passionate group of leaders seeks to reimagine healthcare and create an equitable role for patients, families, caregivers and communities. Ms. Durrah is a first year PhD student in Public Policy with a focus on health policy at the University of Maryland at Baltimore County.

Joe Ferreira, M.B.A., began his role as the Chief Executive Officer and President of Nevada Donor Network in April 2012. Joe brings years of experience and expertise in the Organ Procurement field. He spent 14 years at Life Alliance Organ Recovery Agency in Miami, Florida

where he served as the Director of Clinical Operations for seven years. Joe is a graduate of the University of Miami, with a Bachelor of Science in Microbiology and Immunology. He also received his MBA, with a specialization in HealthCare Administration and Policy, from the University of Miami. He serves as a coach for the Art and Science of Leadership Program at the Wharton School and Fox School of Business. Joe is certified in all aspects of the organ donation and recovery process. Joe is a member of the International Society for Organ Donation & Procurement (ISODP). He is currently serving as the President of the Association of Organ Procurement Organizations (AOPO), as well as served as a Member-at-Large on the (AOPO) Executive Committee. He is a Certified Member of the National Association of Healthcare Quality (NAHQ), and a past Board Member of the Nevada Chapter of the American College of Health Care Executives (ACHE). He has served as the Chairman of the Procurement Council for the Association of Organ Procurement Organizations (AOPO). Joe has also served as an At-Large Representative on four committees of the OPTN/UNOS and currently serves as a Board member of the OPTN/UNOS. Joe is a published author and presenter on organ donation. He has presented at conferences and meetings around the nation and world. He consults internationally and has provided guidance to several foreign governments on the establishment or improvement of organ donation and transplantation systems based on the US model. He was also the recipient of the Kruger Award for Outstanding Professional Transplant Services by the Transplant Foundation in Miami.

Michael Givertz, M.D., Medical Director of the Heart Transplant and Mechanical Circulatory Support Program at Brigham and Women's Hospital and Professor of Medicine at Harvard Medical School. His research interests include cardiorenal syndrome and novel therapies for advanced heart disease. He is a past research fellow of the American Heart Association and recipient of a career development award from the National Institutes of Health. He is currently a principal investigator in the NHLBI Heart Failure Network, and a co-investigator in several other NIH-funded programs, including the NIAID Clinical Trials in Organ Transplantation and NIH Peripartum Cardiomyopathy Network. He is the immediate past chair of the Scientific Statements Committee of the Heart Failure Society of America, co-author of the 2017 ACCF/AHA/HFSA Guideline for the Management of Heart Failure, and lead author of the 2019 HFSA/SAEM/ISHLT Expert Consensus Document on the Emergency Management of Patients with Ventricular Assist Devices. He has published widely on heart failure pathophysiology and management, with a focus on advanced heart disease and mechanical circulatory support.

Alex Glazier, J.D., M.P.H., is President & CEO of New England Donor Services (NEDS), formed in 2017 as an affiliation between two Organ Procurement Organizations (OPOs) together serving over 200 hospitals, 14 transplant centers and a population of 14 million people in a six state service area. Under NEDS, the number of organ transplants increased by 108% in the lower performing OPO service area. As of January 1, 2021, NEDS merged the two OPOs, resulting in the first successful OPO consolidation in decades. NEDS has 270 employees and a \$95M annual operating budget. NEDS was named Modern Healthcare Best Places to Work 2018 and a Top 100 Female Led Business by the Boston Globe and The Commonwealth Institute in 2018, 2019 and 2020. Alex is the Region 1 Councilor on the OPTN/UNOS Board of Directors and Chair of the Policy Oversight Committee leading the strategic coordination of national organ policy development. She previously served on the OPTN/UNOS Membership and Professional Standards Committee and Chaired the Ethics Committee. Alex was twice appointed to the U.S.

Sec of HHS, Advisory Committee on Organ Transplantation (ACOT). Alex is on the Board of the American Society of Reconstructive Transplant (ASRT) and the Board of Donate Life America including work on the venture with Apple to enable donor registration through the iPhone. Previously, Alex was New England Organ Bank's CEO after serving as General Counsel. Alex started her career practicing health law at the firm Ropes & Gray. Alex holds an undergraduate degree in bioethics from Brown University and a JD-MPH from Boston University where she was law faculty.

Susan Gunderson, M.H.A., has dedicated her career to saving lives through organ and tissue donation as founder and CEO of LifeSource. LifeSource is the federally designated organ procurement organization for Minnesota, North Dakota, and South Dakota that saves lives and offers hope and healing through donation and transplantation. LifeSource is widely recognized as a leader in innovation and best practice in organ donation. Ms. Gunderson has held national and international leadership positions, including President, Association of Organ Procurement Organizations and President, International Society for Organ Donation and Procurement; Board director for multiple organizations including the United Network for Organ Sharing, the Alliance for Organ Donation and Transplantation, HHS Advisory Committee on Organ Transplantation, and the Musculoskeletal Transplant Foundation. Since 1996 her international experience has included a faculty appointment with the University of Barcelona, Transplant Procurement Management (TPM) advanced international training course on transplant coordination and she currently serves as Past President of the International Society for Organ Donation and Procurement. She is Associate Editor for *Transplantation* and was a faculty member for the HRSA Organ Donation Breakthrough Collaborative and Organ Transplantation Breakthrough Collaborative. Susan has a strong commitment to community involvement and serves on the St. Olaf College Board of Regents. She received her Bachelor's degree from St. Olaf College and a Masters of Healthcare Administration from the University of Washington.

Richard Hasz, M.F.S., is vice president of clinical services for Gift of Life, where he oversees the day-to-day clinical operations of the program including transplant coordination, hospital development, organ preservation, quality assurance and tissue recovery. Mr. Hasz has 25 years of experience in organ and tissue donation and has served on numerous national leadership committees for the United Network for Organ Sharing (UNOS), most recently on the UNOS Liver and Intestinal Transplantation Committee and Data Advisory Committee. He is a Certified Procurement Transplant Coordinator and Certified Transplant Preservationist. Mr. Hasz has delivered lectures and educational sessions for more than 60 organizations and professional societies. He has also contributed to more than 30 publications in peer reviewed journals to improve the science of donation and transplantation. He has a Bachelor of Science degree in biology from Pennsylvania State University and a master's degree in forensic science from George Washington University.

Burnett "Beau" Kelly, M.D., M.B.A., FACS, FAST, is the Surgical Director at DCI Donor Services, Inc. Dr. Kelly has expertise in liver, intestine, multi-visceral, living donor liver, and split-liver transplantation. In his role at DCI Donor Services he works to improve the quality of organ donation operations, build strong relationships, and bridge trust across the diverse and similar interests of donor hospitals, OPO's, transplant centers, and the community. Dr. Kelly also serves on the board of directors of the American Society of Transplantation.

As a surgeon-scientist, his research identifies variations in transplant outcomes; benchmarks best practices to improve the patient/family experience, and patient throughput back to function in the community. As a scientist/entrepreneur, he has created organ donation research, generated two medical device patents, and developed a pulsatile perfusion program.

Richard Knight, M.B.A., received his MBA from the University of Virginia Darden School of Business and his B.A. from Hampton University. He is a results-oriented business strategist with diverse experience in public and private sectors in Finance, Accounting, Business Development, Healthcare, and Non-Profits. Entrepreneurial experience includes starting and running several ventures. Currently, he is a business strategist, providing patient engagement consulting for healthcare organizations and businesses developing tools designed to leverage patient input and preferences in their care plans and quality measures. He serves as an adjunct professor at Bowie State University (BSU). He is a founding member of BSU's College of Business Advisory Council. Mr. Knight is a healthcare professional and a former hemodialysis patient. He received a kidney transplant approximately fourteen years ago. He is President of the American Association of Kidney Patients (AAKP), which is the oldest and largest, independent kidney patient organization in the United States. Mr. Knight has a background in public policy and Congressional operations based on both his professional experience on Capitol Hill, where he served in various roles including communications, policy, and Legislative Director as well his advocacy work as a kidney transplant patient. While working in the U.S. House of Representatives, Mr. Knight served as a liaison to the Congressional Black Caucus for his Member of Congress. He was involved in substantial work with the House Energy and Commerce and Small Business Committees. Mr. Knight's knowledge of Executive Branch agency budget and procurement policies is based on direct experience as a Federal government contractor and as a ten-year co-chair of the Baltimore Washington Corridor Chamber of Commerce Annual Regional Government Procurement Fair. As a policy expert and a national kidney patient advocate, Mr. Knight was appointed to serve as a member of the National Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council. He was appointed to the Scientific Registry of Transplant Recipients (SRTR) Visiting Committee. Mr. Knight is the CoChair of the NIDDK Strategic Plan Stakeholder Engagement Subgroup. He was also appointed to the Steering Committee for NIDDK's Kidney Precision Medicine Project as well as the Clinical Trials Transformation Initiative (CTTI), which is a public-private partnership to develop and drive adoption of practices that will increase the quality and efficiency of clinical trials. He has served as a member of six Technical Expert Panels (TEPs) for the Centers for Medicare and Medicaid Assistance (CMS). He was a member of CMS TEPs focusing on Emergency Department Readmissions Hospital Readmissions, the Fistula First Breakthrough Initiative, and recently on the End Stage Renal Disease Dialysis Facility Compare Star Ratings for the Arbor Research Collaborative for Health and the University of Michigan Kidney Epidemiology and Cost Center. He serves on the National Kidney Disease Education Program's (NKDEP) Health Information Technology (HIT) Working Group. He also serves on the Steering Committee for the Precision Medicine Coalition's More Than a Number Committee. Mr. Knight also serves on numerous Advisory Councils for industry partners on matters such as increasing patients in clinical trials and increasing minority participation in clinical trials.

Gabriela Landeros-Williams is a Benefits Navigator at DaVita Kidney Care where she is a resource for their dialysis patients. Gaby became involved as a volunteer at Donor Alliance in 2014 following the passing of her sister. At Donor Alliance she became their first Communications and PR Intern, a role that she greatly enjoyed. Volunteering with Donor Alliance made her feel closer to her sister Diana. It also helps Gaby keep Diana's memory alive. Currently, Gaby is looking into furthering her studies in the field of psychology.

Keren Ladin, Ph.D., M.Sc., is Associate Professor in the Departments of Occupational Therapy and Community Health at Tufts University. She is Director of Research on Aging, Ethics, and Community Health (REACH Lab) at Tufts University. Her scholarly work examines questions of equitable allocation of health resources, shared decision-making, and disparities. Dr. Ladin has published extensively on topics related to transplantation, aging, kidney disease, and health disparities, and is an expert in mixed-methods, medical ethics, and health policy. She currently serves as Chair of OPTN/UNOS Ethics Committee. Dr. Ladin's research has been funded by the Greenwall Foundation, the Patient Centered Research Outcomes Institute (PCORI) and the National Institutes of Health. At Tufts, Dr. Ladin teaches courses in health policy, research methods, public health ethics, and health disparities. Dr. Ladin studied History, Philosophy, and Social Studies of Science and Medicine as an undergraduate at the University of Chicago. She received her masters degree in Population and International Health from the Harvard School of Public Health, and her PhD in Health Policy, with a concentration in ethics, from Harvard University.

Alexandre Loupy, M.D., Ph.D., is the team leader of an epidemiology research team at the National Institute of Health and Medical Research (Inserm) U970. He is also a professor of Nephrology working in the kidney transplant department of Necker Hospital. He founded the Paris Transplant Group in 2008. His research focuses on artificial intelligence and multi-organ transplantation analytics. It covers allograft transplantation, rejection, antibodies and populational sciences. Pr. Loupy defended two PhDs, one in cell biology (2011) and the other in biostatistics (2014). Since 2015, Pr. Loupy is the head of the Paris Expertise Centre for Organ Transplantation in PARCC U970. The Paris Transplant Group is recognised in the transplant research field for high impact factor quality epidemiologic research and has changed clinical practice with wide implementation of discoveries into clinical practice. Pr. Loupy has also been appointed Professor of Nephrology and Epidemiology Kidney Transplant department at the Necker Hospital in Paris, France in 2017 and adjunct Professor at Cedars Sinäi, UCLA, California, USA, in 2020. Pr. Loupy has been appointed as Director of the Banff Scientific Committee for allograft classification in 2014 and contributes to the working groups (22 transplant centres represented worldwide), and Banff recommendations delivered to the international transplant community. Pr. Loupy is also an expert for the FDA and a member of the American Society of Transplantation. He got the Clinical science investigator award from the AST in 2017 and was awarded the National Academy of Medicine Award for his work on "Renal transplantation, anti-HLA graft rejection, and biomarker identification". Dr Loupy is also involved in the French Society of Transplantation and in the European Society of Transplantation. Pr. Loupy was Associate Editor for the Transplantation Journal from 2014 to 2018, and still is at the American Journal of Transplantation. He is also referee for the New England Journal of Medicine, Nature Medicine, The Lancet, JAMA, the American Journal of Transplantation, Kidney International, Plos Medicine and the Journal of the American Society of

Nephrology. In the past years, Pr. Loupy has obtained several grants to implement cutting edge diagnostic tests at large scale. Pr Loupy is principal investigator and coordinator of international H2020 (EU-TRAIN) and national RHU (KTD-innov, iTRANSPLANT) projects. He is also PI or co-PI of several on-going clinical trials since 2018.

Sumit Mohan, M.D., is an associate professor of medicine & epidemiology at Columbia University. Dr. Mohan's clinical and research career has been focused on understanding the health disparities in kidney disease with a goal of improving access to care and outcomes for patients with kidney disease – especially those with end stage kidney disease and kidney transplantation. His research findings have directly informed federal policy related to reimbursement of dialysis for acute kidney injury, elimination of outcomes as a regulatory measure for transplant centers as well as efforts to lower the discard of deceased donor kidneys in the United States. He is currently the vice chair of the OPTN/UNOS data advisory committee, a member of the OPTN/UNOS policy oversight committee, SRTR Review Committee and the CMS kidney transplant collaborative and the Deputy Editor for *Kidney International Reports*.

Robert Montgomery, M.D., D.Phil., is the H. Leon Pachter Chair and Professor of Surgery, 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. His academic interests include HLA sensitization, tolerance protocols including simultaneous solid organ and bone marrow transplantation, 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. In 2018, he became a recipient of a

heart transplant from a Hepatitis C positive donor and has worked to try to promote this practice throughout the world.

Kenneth P. Moritsugu, M.D., M.P.H, F.A.C.P.M, lost his wife, Donna Lee Jones Moritsugu, in an automobile crash in 1992, and his daughter Vikki Lianne in a separate automobile crash in 1996. Both were organ and tissue donors. He has been intimately and extensively involved with organ and tissue donation and transplantation ever since. Dr. Moritsugu recently retired from the Board of Directors for the Washington Regional Transplant Community, where he had served as a public representative for over twenty-five years. He has spoken extensively both internationally and domestically on organ and tissue donation; and in 2007, the International Organ Donation Congress named him the first International Ambassador for Organ and Tissue Donation. In January of 2016, he organized a plenary panel of former Surgeons General of the United States for the mid-winter meeting of the American Society of Transplant Surgeons (ASTS), addressing “Transforming the Landscape of Organ Access and Transplantation: Surgeons General Perspectives.” He was a keynote speaker at the White House Summit on Organ Donation; and in January 2017, ASTS deemed him an Honorary Member of the society. Over his long involvement, he served as a principal speaker for the National Organ Donation and Transplantation Collaboratives, from 2004 through 2007, and has been a regular feature at the National Donor Family Recognition Ceremonies in Washington, DC. In 2016, he served as a member of the Committee on Issues In Organ Donor Intervention Research, of the National Academies of Science, Engineering, and Medicine. Rear Admiral Kenneth Moritsugu was the Acting Surgeon General of the United States, in 2002 and again from July 2006 until his retirement from the Commissioned Corps of the United States Public Health Service (USPHS) in September 2007. As Acting Surgeon General, he served as the nation’s top doctor, communicating the best available science and information to the American people to help protect, promote, and advance their health and safety. In this position, he also was the operational commander of the 6,500 Commissioned Corps health personnel of the USPHS. As of October 1, 1998, he served as the Deputy Surgeon General of the United States. A career officer in the Commissioned Corps of the USPHS for 37 years, Admiral Moritsugu held the title of Assistant Surgeon General since 1988, beginning with the tenure of Surgeon General C. Everett Koop. He is currently the Principal at First Samurai Consulting, LLC, a firm specializing in health consultations, “putting the patient at the center of what we do.” Dr. Moritsugu was born and raised in Honolulu, Hawaii. After attending Chaminade College, he received his Baccalaureate Degree with Honors in Classical Languages from the University of Hawaii in 1967, a Medical Doctor degree from the George Washington University School of Medicine in 1971, and a Master of Public Health in Health Administration and Planning from the University of California, Berkeley, in 1975. Dr. Moritsugu is Board Certified in Preventive Medicine; holds Fellowships in the American College of Preventive Medicine, the Royal Society of Public Health, the Royal Society of Medicine, and the National Academy of Public Administration; and is a Certified Correctional Health Professional. Over his public career, RADM Moritsugu served in many diverse assignments in uniform, including Staff Medical Officer at the USPHS Hospital Outpatient Department in San Francisco; Medical Officer on board the U.S. Coast Guard Cutter Taney (Ocean Station Bravo); Director of the National Health Service Corps; and Assistant Bureau Director and the Medical Director of the U.S. Department of Justice’s Federal Bureau of Prisons, in addition to Deputy Surgeon General. Admiral Moritsugu has received numerous honors and awards, including the Surgeon General’s Medallion with two gold stars, twelve

honorary degrees, and Distinguished Service Medals from the USPHS, the Federal Bureau of Prisons, and the Uniformed Services University of the Health Sciences. Also an educator, Dr. Moritsugu is an Adjunct Professor of Global Health at the George Washington University School of Public Health and Health Services, and Adjunct Associate Professor of Preventive Medicine at the Uniformed Services University of the Health Sciences. Dr. Moritsugu resides in Sarasota, FL, with his wife, Lisa R. Kory. He has two daughters, Erika Elizabeth Moritsugu, an attorney in Washington, DC; and Emily Renee Moritsugu.

David Mulligan, M.D., is an abdominal organ transplant surgeon performing both living and deceased donor liver, kidney, and pancreas transplants. He currently serves as professor and chair of transplantation and immunology in the Department of Surgery at Yale School of Medicine/Yale New Haven Health System. His clinical and academic focus surrounds living donor liver transplantation, expanding donation, and working on ways to utilize ex-vivo organ perfusion systems to increase transplantation in the United States. Dr. Mulligan and his team are testing novel strategies in immunosuppression; improved biomechanical organ preservation methods to reduce ischemia/reperfusion injury and promote regeneration; and working in the field of 3D bioprinting to collaborate in finding ways to grow new organs from stem cell precursors. He has performed more than 200 living donor transplants and has authored more than 180 publications. He also has served on numerous editorial review boards and presented across the U.S. and internationally. Dr. Mulligan's leadership in solid organ transplantation across national and international platforms has grown considerably and he now serves as president of the United Network of Organ Sharing (UNOS)/Organ Procurement Transplant Network (OPTN), member at-large on the Governing Board of the American Association for the Study of Liver Diseases, chair of the Advisory Council on Transplantation (ACOT) to the Secretary of HHS, special government employee for FDA Medical Device Advisory Committee and chair of the Business Practice Committee of the American Society of Transplant Surgeons. In these visionary roles, he has led major changes in organ allocation and distribution and will hopefully culminate in substantial increases in organ transplants. Passionate about patient-centered care and building more resilient teams, he makes time to share his enjoyment of spending time in nature, especially near the ocean, with his wife and three children.

Howard M. Nathan is the longest-serving Chief Executive of any organ procurement organization in the United States, recently celebrating his 42nd anniversary with Gift of Life Donor Program in July 2020. Since 1974, the program has coordinated more than 52,500 organs for transplantation and approximately 1.75 million tissue transplants. Gift of Life is one of the oldest of the 57 organ procurement organizations in the United States and under Mr. Nathan's leadership has grown to be the largest organ donation program in the country, with a network of 15 transplant centers with 40 organ-specific programs and 128 donor hospitals. In 2020, for the 13th consecutive year, Gift of Life Donor Program is the nation's leading OPO, coordinating 619 organ donors, resulting in 1,619 organ transplants, the most life-saving organs for transplant among all U.S. OPOs. Considered one of the nation's leading authorities on organ and tissue donation, Mr. Nathan is a regular presenter at national and international organ and tissue procurement, transplantation, and medical/healthcare conferences. He and has published more than 400 scientific papers and abstracts during his career and has travelled to over 30 countries to promote best practices in organ donation and transplantation. He has served on numerous leadership boards including: United Network for Organ Sharing (UNOS), Association of Organ

Procurement Organization (AOPO), North American Transplant Coordinators Organization (NATCO), International Society for Organ Donation and Procurement (ISODP), Donate Life America (DLA), LifeLogics Inc., MTF Biologics (MTF) Board of Trustees, National Disease Research Interchange (NDRI), National Kidney Foundation (NKF), Organ Donation & Transplantation Alliance (The Alliance), and the Governor Robert P. Casey Memorial Trust Fund Organ Donation Advisory Committee (ODAC), Commonwealth of Pennsylvania, among others. Mr. Nathan has appeared on hundreds of local, national and international television news and talk shows and has received numerous outstanding achievement awards, most recently Lions Eye Bank of Delaware Valley “Knight of the Blind” Award (2017), Juniata College “Alumni Achievement Award” (2017), Donate Life America “Nicholas Green Lifetime Achievement Award” (2017), Transplant Recipients International Organization, Inc. (TRIO) Lifetime Achievement Award (2018), the Association of Organ Procurement Organizations (AOPO) President’s Award (2018), and Main Line Today “Healthcare Heroes” Award (2019).

Kevin O’Connor, M.S.A., has served as President and CEO of LifeCenter Northwest (WALC) since 2010. From 1983 through 2009, he served in various clinical and leadership positions at New England Organ Bank, rising to Senior VP for Organ Donation Operations before moving west. Prior to this, he worked as a Cardiothoracic Surgical PA in Boston. In 2018, he served as Chair of the OPTN Ad Hoc Geography Committee. He is currently a member of the OPTN Liver and Intestinal Transplant Committee, and has served on the OPTN Board of Directors, as well as the Kidney Committee, the Kidney Allocation Review Subcommittee, the Operations Committee, the Membership and Professional Standards Committee, and several other OPTN committees. He has been active on AOPO Committees as well, including the Legislative & Regulatory Affairs Committee (Chair, 2017), the OPO Metrics Workgroup, two Future Initiatives Workgroups, and in a variety of other roles. He currently serves on the board of four organizations. He has authored or co-authored over 30 papers and four book chapters, on topics including the organ donation process, organ donor evaluation, donor management, improving kidney utilization, and donation after circulatory death.

Richard V. Perez, M.D., is Chief of the Division of Transplantation, in the Department of Surgery at the University of California, Davis Medical Center, where he has been a faculty member for close to 30 years. He has led the transplant program, which has successfully expanded the pool of kidneys available for transplantation and has consistently been a national leader in the volume of deceased donor kidney transplants annually. Dr. Perez has been a long-time advocate of organ donation locally and nationally, participating in many public awareness and educational activities. He has served on the Advisory Board for the regional organ procurement organization, Sierra Donor Services, as well as several committees and on the Board of Directors of the United Network for Organ Sharing (UNOS).

Charles Rosen, M.D., is a Professor of Surgery in the Division of Transplantation surgery at Mayo Clinic Rochester. His clinical practice is focused on liver transplantation. He currently serves as the Medical Director for Contracting and Payer Relations for Mayo Clinic. He served as Director of the William J. von Liebig Center for Transplantation and Clinic Regeneration at Mayo Clinic Rochester (2017 – 2019), Chair of the Division of Transplantation Surgery (1999 – 2017) and Surgical Director of Liver Transplantation at Mayo Clinic (1998 – 2008). He has also served as President of the Board of Directors and Medical Director for LifeSource (2007 –

2008), the organ procurement organization serving Minnesota, North and South Dakota. He served as faculty co-chair for the HRSA Transplant Center Growth and Management Collaborative 2007 – 2008 and was a member of the faculty of the HRSA Organ Donation and Transplantation Collaborative 2005 – 2006. He graduated from Phillips Exeter Academy in 1977 and received his bachelor's degree in biochemistry from Harvard University in 1980. He received his medical degree from Mayo Medical School in 1984. He completed a residency in general surgery in 1989 and a fellowship in transplantation surgery in 1991 at the Mayo Graduate School of Medicine. Prior positions include Surgical Director of Liver Transplantation at Saint Luke's Hospital of Kansas City (1991 - 1993), Senior Associate Consultant in Transplantation Surgery at Mayo Clinic Rochester (1993 – 1994), and Associate Professor of Surgery in the Division of Transplantation Surgery at the University of Florida (1995 – 1998). Academic and clinical areas of interest include liver transplantation, living donor liver transplantation, transplantation for cholangiocarcinoma and other hepatobiliary tumors, and deceased donor organ utilization and procurement.

Deanna Santana currently serves as the Director of Programs for Child Advocates of El Dorado, an organization serving children in foster care. Previously, she was the Public Education Manager for Sierra Donor Services, the organ procurement organization (OPO) serving the greater Sacramento area for over eight years. In this role, she acted as the public relations specialist and family services liaison; telling the stories of donation with the media, handling crisis communications, and connecting donor families to the recipients of their loved ones when desired and possible. Deanna joined the staff of the OPO following the death and organ/tissue donations of her son, Scott, in 2011. Scott was an organ, eye and tissue donor and Scott's entire family began to volunteer shortly after his death to encourage others about joining the Donate Life Registry. In 2015 Deanna was elected to the OPTN/UNOS board of directors as a donor/patient representative and elected in 2018 as the Vice President of Donor/Patient Affairs. While on the board, she participated in many committees including the Donor/Patient Affairs Committee, the Taskforce on Geography, the Executive Committee and the Corporate Affairs Committee. She has also served on several Donate Life America committees and held the position of Vice-Chair of the advisory council in 2019. After seeing the ever growing waitlist of those in need of a life-saving organ transplant, she donated a kidney to a stranger in 2015 and kicked off a chain in which four people received a transplant. She often speaks of her son saving five lives through organ donation but in reality he is responsible for saving nine because before his donation she had no connection to the transplant/donation field and believed everyone received a transplant when placed on the "list."

Mark Schnitzler, Ph.D., is a Professor of Surgery, and Director of Research and Quality in the Center for Abdominal Transplantation at Saint Louis University. In addition to training in economics and statistics, he received clinical training in transplant nephrology at Washington University in St. Louis, MO, through an NIH K25 Career Development Award. He has more than 25 years of experience in the regulatory, technical and analytic issues related to the construction and analysis of integrated transplant registry, administrative health insurance databases, and cost accounting databases to address clinically relevant topics in transplant practice and policy, including issues related to living organ donation and deceased donor organ allocation. He has provided economic and health outcomes analysis services to the Organ Procurement and Transplant Network (OPTN), the United Network for Organ Sharing (UNOS),

the Centers for Medicare & Medicaid Services (CMS), the United States Department of Health and Human Services, members of the United States House of Representatives and Senate, the President's Advisory Committee on Organ Transplantation and others. To date he has co-authored >200 Medline-referenced articles, in journals including the New England Journal of Medicine, JAMA, the Annals of Internal Medicine and others.

Laura Siminoff, Ph.D., is the Dean of the Temple University College of Public Health and a Laura H. Carnell Professor. Dr. Siminoff holds a doctorate in public health from the Johns Hopkins Bloomberg School of Public Health. She is an internationally renowned public health scientist and an expert in health communication. Dr. Siminoff has spent over 25 years conducting groundbreaking work in the field of organ and tissue donation for both transplantation and research. The need for transplantable organs to treat major organ failure has reached crisis proportions with over 110,000 Americans on the transplant waitlist. Her work, which has elucidated the ethical and social issues surrounding the decisions of family decision makers at the bedside to donate or not, has influenced US policy and law in this field. Dr. Siminoff's seminal study in this area was the first ever to collect primary data from multiple sources to examine the policies concerning required request laws and demonstrated that there was a significant reluctance on the part of the US public to donate organs for transplantation. Since then, she has demonstrated which policies might be most successful in attenuating the shortage and has focused on the need to prioritize the dearth of donors which is fueling the organ shortage. She has created innovative training to assist Organ Procurement Organization donation professionals more effectively discuss the donation option with grieving families and has extended these to donation of tissue for genetic research. Her communication intervention, Communicating Effectively about Organ Donation (CEaD), has been developed to include interactive videos and simulation across a range of donation situations. This approach is making communication skills training more readily accessible to OPO staff around the country. Recently, she led studies to understand the ethical and social implications of tissue donation for the Genotype Tissue Expression (GTEx) study, an NIH director's project. Her work importantly encompasses examination of diverse populations, including Black Americans, Asians and Hispanics. Her current funded research is studying the barriers to donation among Asian Americans (NIH) and the challenges and opportunities for Vascularized Composite Allograft Vascularized Composite Allograft transplantation (VCA) donation to treat traumatic injuries (US Department of Defense). She is the author of over 185 scientific articles and book chapters.

Jon Snyder, Ph.D., M.S., serves as the Director of Transplant Epidemiology for the Chronic Disease Research Group of the Hennepin Healthcare Research Institute (HHRI). He has been with HHRI since 1999 working in the field of solid organ transplantation. He has operated the Scientific Registry of Transplant Recipients (SRTR) since 2010, serving as the Director of the SRTR since 2019. He is a member of the American Society of Transplantation and The Transplantation Society, and he serves on the Board of Directors of Donate Life America and the Organ Donation and Transplantation Alliance. He was the recipient of the 2014 Executive Director's Award given by the Association of Organ Procurement Organizations, and he serves on the Clinical Policy Board of LifeSource. He has co-authored more than 100 publications and is currently a Statistical Editor of the American Journal of Transplantation and an Associate Editor of Transplantation. Dr. Snyder earned his Doctorate in Epidemiology and his Masters in Biostatistics from the University of Minnesota, where he is also an Associate Professor of

Medicine and an Adjunct Assistant Professor in the Division of Epidemiology and Community Health.

Brigitte E. Sullivan, M.B.A., has over 25 years of experience in organ transplantation administration. In her role as the Executive Director of the NYU Langone Transplant Institute, Brigitte is responsible for management of the center's clinical operations, finances, regulatory compliance, quality improvement activities, community outreach and education, data systems and strategic business development. Brigitte has served as Chair of the Board of Directors of the Living Legacy Foundation, Secretary of the National Kidney Foundation, a member of the United Network for Organ Sharing Transplant Administrators Committee, a member of the Live On NY Board of Directors, and participates in various other local and national societies and panels in the support of transplantation and organ donation. She holds an MBA from the Johns Hopkins University, and a degree in film and television from the NYU Tisch School of the Arts. Prior to starting her career in healthcare, she was an officer in the U.S. Army.

Maryam Valapour, M.D., M.P.P., is Director of Lung Transplant Outcomes at the Respiratory Institute. A practicing pulmonologist, Dr. Valapour has worked in the field of lung transplantation for 18 years and has extensive clinical expertise in the care of lung transplant candidates and recipients. Dr. Valapour is focused on research to improve the U.S. lung transplant system and the outcomes of transplant patients. She serves as Principal Investigator on a number of grants addressing patient- and system-level approaches to improve lung transplantation. Dr. Valapour holds an R01 grant from the National Institutes of Health to develop an improved risk-modeling approach to help prioritize patients with advanced lung diseases for lung transplant. She is the Principal Investigator for the Cystic Fibrosis Lung Transplant Consortium (CFLTC) award where the Cleveland Clinic is one of fifteen North American institutions participating in a clinical and translational network of Cystic Fibrosis (CF) lung transplant centers. The goal of this award is to facilitate lung transplant research for candidates and recipients with CF and other advanced lung diseases. Dr. Valapour is also Co-Principal Investigator for the CFLTC Biorepository Coordinating Center where she and her team of investigators will provide scientific expertise and infrastructure to understand the pathogenesis of chronic transplant rejection and develop new therapies to improve outcomes for lung transplant patients. In addition to her roles at the Cleveland Clinic, Dr. Valapour serves as Senior Investigator for Lung Transplantation for the U.S. Scientific Registry of Transplant Recipients (SRTR). In this role, she oversees the analysis of all U.S. lung transplant data and refinement of the lung allocation system. She serves as scientific advisor to the U.S. Organ Procurement and Transplantation Network (OPTN)/United Network for Organ Sharing (UNOS) Thoracic Committee. Dr. Valapour earned her medical degree from the Medical University of South Carolina and completed residency in Internal Medicine at Thomas Jefferson University. She did fellowship training in Pulmonary and Critical Care Medicine at Johns Hopkins University. In addition, she completed fellowship training in Bioethics and Health Policy at Johns Hopkins University and earned a Master in Public Policy from Humphrey School of Public Affairs, University of Minnesota.

Kelly Watson, R.N., has over 18 years' experience as a Registered Nurse including 6 years in transplant. In her role as a Pre Lung Transplant Nurse Coordinator at University of North Carolina Health Center for Transplant Care, she is responsible for helping patients navigate the

transplant system requirements, waitlist management, and taking donor call. Kelly also serves as the Team Lead for the Lung Transplant Team which requires her oversight and participation in the day to day operations throughout the entire continuum of lung transplant. Prior to transplant, Kelly was a charge nurse in the UNC Health Pediatric Intensive Care Unit and she holds a BSN from The University of North Carolina Chapel Hill.

Aaron Wightman, M.D., M.A., is a pediatric nephrologist and bioethicist at the University of Washington School of Medicine, Seattle Children's Hospital and the Treuman Katz Center for Pediatric Bioethics. His research interests focus on medical decision-making for children with complex, chronic medical conditions. He is the founder and chair of the ethics committee for the American Society of Pediatric Nephrology and serves on the UNOS ethics committee.

Christopher Zinner leads the Digital and Customer Experience practice within Accenture Federal Services. He specializes in helping organizations transform their customer experience through strategy and technology implementations, leveraging digital at every step of the way. He also founded the Accenture Federal Digital Studio, which brings the innovative Human Centered Design (HCD) practices to federal agencies. He has led transformational programs across both private sector, public sector, and non-profit industries including clients such as CMS, FDA, NIH, NASA, USAA, Sprint/Nextel, US Census Bureau, SEC, US Army, IRS, Marine Corps Community Services, and the World Economic Forum. Chris has been with Accenture for 22 years. Prior to Accenture, he served as an officer in the US Army for four years.

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February 4 & 5, 2021
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Speaker Guidance Questions

QUESTIONS TO BE CONSIDERED BY ALL SPEAKERS:

1. What are the key attributes of a fair, equitable, and transparent deceased organ donor system?
2. How will we know we have achieved a fair, equitable, and transparent system?
3. What barriers must be overcome or changed to implement a fair, equitable, and transparent system?
4. What specific actions must be taken to make the system more fair, equitable, and transparent?

SESSION I: BIOETHICAL CONSIDERATIONS OF FAIRNESS, EQUITY, AND TRANSPARENCY

Speakers: James Childress, Alexandra Glazier

1. (*Childress*) What do the terms “fairness,” “equitable,” and “transparency” currently mean when applied to the deceased donor organ transplant system?
2. (*Glazier*) How do current laws consider, prioritize, or hinder fairness, equity, and transparency?
3. (*Childress and Glazier*) What does a fair, equitable, and transparent deceased donor organ system look like? How will we know we have achieved a fair, equitable, and transparent system?
4. (*Childress and Glazier*) Can we measure these concepts so that we can work towards and continuously improve the fairness, equity, and transparency of the system? Do appropriate and validated performance measures of these concepts currently exist?

SESSION II: THE U.S. ORGAN PROCUREMENT SYSTEM

Speakers: Howard Nathan, Susan Gunderson, Kevin O'Connor, Richard Perez, Joe Ferreira, Alexandra Glazier, Diane Brockmeier

1. *(Nathan)* How did the current role of OPOs develop? How has the role of the OPO changed over the years? How do OPOs interact with transplant centers, donor hospitals, and the public?
2. *(Nathan)* Can you provide a brief history of DSA boundaries and identify any considerations of equity or fairness with regard to DSAs?
3. *(Gunderson)* Can you provide an overview of the organ donation process (e.g., referral, authorization, donor management, organ preservation, organ allocation, quality systems and donor family aftercare)? How is the organ quality assessed and how can that assessment vary across OPOs? Is there a role for standardizing organ assessment criteria?
4. *(O'Connor, Perez)* Please provide your perspectives on challenges and opportunities in organ utilization. What are the challenges and opportunities for transplant centers and OPOs in the era of broader organ distribution? How important are the relationships between OPOs and transplant centers and how have these relationships changed with broader organ distribution? Are there models of highly successful relationships between OPOs and transplant centers?
5. *(Ferreira)* Can you comment on the acceptance of organ donation in diverse communities including perspectives on authorization (e.g., registries)? How are OPOs engaging with various communities, including those that are underserved? What are the challenges and opportunities?
6. *(Glazier)* How can technologies such as perfusion machines and automated referrals improve OPO processes? Are there other innovative approaches that could be utilized by OPOs to improve donation and transplant rates?
7. *(Brockmeier)* How are some OPOs utilizing donor recovery centers to optimize their processes? What are the various models that OPOs use to recover organs? What are some barriers to implementing donor recovery centers more broadly?

SESSION III: TRANSPLANT CENTER OPERATIONS AND ORGAN ACCEPTANCE DECISIONS

Speakers: Sumit Mohan, Kelly Watson, Rick Hasz, Brigitte Sullivan, and Alexandre Loupy

1. Please provide your perspectives on challenges and opportunities in organ utilization. What role do transplant centers and OPOs play in the era of broader distribution of deceased donor organs? Are there other innovative approaches that could be utilized by OPOs and/or transplant centers to improve donation and transplant rates?
2. What actions could be taken to incentivize the acceptance and successful use of more organs, especially marginal organs, by transplant center physicians and patients (including on weekends)?
3. What role do transplant centers play in improving access to waitlists for underserved populations?
4. Describe the role of transplant centers in managing various waitlists – where are the challenges and opportunities for improving waitlist management? What does intense, aggressive, and successful management of a transplant waiting list look like?
5. Why are organs declined in general and for a specific patient? How much do patients generally know about the declines and acceptance of organs offered for them? Does transparency need to be improved between transplant center physician and patient and, if so, what would be the expected impact of increased transparency on overall organ utilization?

6. What are your suggestions for increasing access to organ transplantation for vulnerable and underserved populations?

SESSION IV: DATA COLLECTION AND MODELING

Speakers: David Mulligan, Jon Snyder, Nikhil Agarwal, and Michael Givertz

1. (*Mulligan*) What role does data collection and modeling play in determining the suitability of a proposed organ allocation policy change? Can you describe your experience with data collection and modeling when you were a part of the committee that considered changes to liver allocation?
2. (*Snyder*) What role does the SRTR play in studying changes to the organ allocation system? Please provide a brief overview of simulated allocation models (SAMs) and their strengths and limitations, including data availability.
3. (*Agarwal*) What is the latest thinking in the economics and/or computer science community about how to simulate systems so that the impact of changes to those systems can be studied?
4. (*Givertz*) From your research, how well do you think models correlate to the impact of actual organ allocation policy changes? What can the models potentially tell us about some of the intended and unintended consequences?
5. (*all speakers*) What aspects of modeling reports look at potential disparities? Are these assessments accurate and complete? What can be learned and what is missing?

SESSION V: PUBLIC COMMENT PERIOD

SESSION VI: EXPLORING DISPARITIES AND ACCESS ISSUES IN ORGAN PROCUREMENT, ALLOCATION, AND DISTRIBUTION

Speakers: Kimberly Jacob Arriola, Laura Siminoff, Lilia Cervantes, Burnett (“Beau”) Kelly, Keren Ladin, Maryam Valapour, and Aaron Wightman

1. What is known about inequities and/or disparities in deceased donation? In the organ procurement system? In deceased donor organ allocation? And in organ distribution?
2. What disparities exist around getting on (and staying on) a waitlist to receive a donor organ?
3. Which communities are most affected by disparities/inequities in the organ procurement, allocation, and distribution system? From your perspective, are there opportunities to address or mitigate these disparities? What steps could be taken to make the system more fair and equitable?

SESSION VII: DECEASED DONOR FAMILY PERSPECTIVES

Speakers: Gabriela Landeros-Williams, Deanna Santana, and Kenneth Moritsugu

1. If your deceased family member was a registered organ donor, what affect did this have on decisions made in relation to the donation?
2. If your deceased family member was not a registered organ donor, what factors were considered during the decision making process?
3. Could any improvements in the care system have made your experiences more informed or positive?
4. How important are the logistics (location, timing) of the donation operation to a donor family? If the donation was delayed by hours or even days, but more organs could be used, how would that be perceived by donor families?
5. How did the recipient of the organs play into your decision making? Did you feel strongly about who received the organs? Do you think factors about the potential recipients are something considered by donor families?
6. What do you remember most about your experience?
7. Did you and your family receive helpful resources and feel supported by the organ procurement organization staff and other professionals you encountered during your experience?

SESSION VIII: TRANSPLANT RECIPIENT PERSPECTIVES

Speakers: Alexis Conell, Hala Durrah, Richard Knight, and Robert Montgomery

1. How did you weigh the decision to accept or decline a particular donor organ? Did family considerations (e.g., care plans) play into your decision?
2. What was/were the one or two most important factors in your decision making process?
3. Do you feel that enough information was provided to make an informed decision?
4. Could any improvements in the care system have made your experiences more informed or positive?
5. What do you remember most about the whole process of making a decision?
6. What was your role and your physician's role in making decisions about organs that were being offered to you? To what extent were you involved in that process?

SESSION IX: COSTS AND OTHER ECONOMIC FACTORS

Speakers: Charles Rosen, David Axelrod, Mark Schnitzler, and Christopher Zinner

1. What is known and unknown about costs in the system? Who is paying those costs (e.g., federal government, private payers, institutions, patients)?
2. Which costs are born by patients that may affect their receiving, or not receiving, an organ?
3. Where can we find opportunities to save? Where can costs not be compressed?
4. Where can we invest in order to save more? How much would it be reasonable to invest in more organ procurement?
5. To what extent do costs contribute to inequities in transplantation? What solutions or policies might help address some of the cost factors that contribute to inequities in transplantation?

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