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

PUBLIC LISTENING SESSION

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

Thursday, July 15, 2021

11:00 AM - 3:15 PM ET

PUBLIC LISTENING SESSION OBJECTIVE

Give members of the public and stakeholders in the transplant community an opportunity to share their comments and ideas with the committee for creating a fairer, more equitable, cost-effective, and transparent system of donor organ procurement, allocation, and distribution.

11:00 a.m. Welcome and Introductions

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

11:05 a.m.Creating a Fairer and More Equitable System: Are There Structural Barriers
Embedded in the Path to an Organ Transplant in the U.S.? (5 minutes each)

- Donna Handy, Patient, Massachusetts General Hospital
- Ashley Helsing, Director of Government Relations, National Down Syndrome Society
- **Robert Higgins**, Director of the Department of Surgery, Johns Hopkins University School of Medicine
- Kelly Israel, Policy Associate, Autistic Self Advocacy Network
- Jayme Locke, Director, UAB Comprehensive Transplant Institute
- Jerry McCauley, Medical Director of Transplantation Services, Thomas Jefferson University; Vice President, United Network for Organ Sharing (UNOS)
- Brian Shepard, CEO, UNOS

- Sridhar Tayur, University Professor of Operations Management, Carnegie Mellon University
- **Fanny Vlahos**, attorney; double lung transplant recipient; member of the Lung Transplant Initiative and Guidelines Committee, Cystic Fibrosis Foundation
- Janet Weiner, Board Member, Cystic Fibrosis Foundation (Washington, DC chapter)
- Charlotte Woodward, Community Outreach Associate, National Down Syndrome Society

12:00 p.m. Clarifying Questions from the Committee

12:10 p.m. Maximizing Public and Professional Trust: What Steps Can Be Taken to Build a More Transparent and Accountable System? (<u>5 minutes each</u>)

- David Goldberg, Associate Professor of Medicine, University of Miami
- Martin Hatlie, President and CEO, Project Patient Care
- **Emily Largent**, Emanuel & Robert Hart Assistant Professor of Medical Ethics and Health Policy, University of Pennsylvania
- **Raymond Lynch**, Associate Professor of Surgery and Director of Public Policy and Community Relations, Emory Transplant Center
- Virginia (Ginny) McBride, Executive Director, OurLegacy
- **Constance Mobley,** Associate Director of Liver Transplantation, Houston Methodist J.C. Walter Jr. Transplant Center
- Blair Sadler, Senior Fellow, Institute for Healthcare Improvement
- **Greg Segal,** CEO, Organize
- **Marion Shuck,** President, Association for Multicultural Affairs in Transplant (AMAT)
- 12:55 p.m. Clarifying Questions from the Committee
- 1:05 p.m. **BREAK**

1:25 p.m. Aligning Incentives: What Can Be Done to Increase the Efficiency and Effectiveness of the Organ Transplant System? (<u>5 minutes each</u>)

- Clive Callender, Professor of Surgery, Howard University of Medicine
- **A. Osama Gaber,** Chair, Houston Methodist Department of Surgery and Incoming President, American Society of Transplant Surgeons (ASTS)
- Michele Bratcher Goodwin, Director, Center for Biotechnology & Global Health Policy, University of California, Irvine School of Law
- Paul Myoung, Senior Administrative Director, Massachusetts General Hospital
- Howard Nathan, President, Gift of Life Donor Program
- Marty Sellers, Associate Professor of Surgery, Emory University; Associate Medical Director, LifeLink
- Janice Starling, Founder, All Kidney Patients Support Group
- 2:00 p.m. Clarifying Questions from the Committee
- 2:10 p.m. Increasing Rates of Organ Donation and Acceptance: What Steps Would Save More Lives of Those On the Waitlist? (<u>5 minutes each</u>)

- Jennifer Erickson, Innovation Fellow, Federation of American Scientists
- Richard Formica, Past President, American Society of Transplantation
- Kevin Fowler, Consultant, The Voice of the Patient, Inc.
- Kevin Longino, CEO, National Kidney Foundation
- Jerold Mande, Visiting Fellow, Tisch College of Civic Life, Tufts University
- Melissa McQueen, Transplant Families
- **Patti Niles,** CEO, Southwest Transplant Alliance
- Velma Scantlebury, Professor of Surgery, University of North Texas Health Science Center
- Quin Taylor, Founder, Tayloring Gratitude
- Janice Whaley, President & CEO, Donor Network West

3:00 p.m. Clarifying Questions from the Committee

3:10 p.m. Closing Comments

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

3:15 p.m. Adjourn