



Fourth Roundtable Event

Organ Donation and Access to Transplantation

December 9, 2016 from 8:30am to 3pm

The Rogosin Institute's

Jack J. Dreyfus Center for Health Action and Policy

Maurice R. and Corinne P. Greenberg Center for Integrative Healthcare

619 West 54th Street, 4th Floor, New York, N.Y. 10019

Moderator: Dr. Barry Smith

8:30	Light Breakfast	
9:00	Welcome	Dr. Barry Smith
9:05	Short Self-Introductions	All Participants
9:30	Keynote	Dr. Adam Bingaman
10:00	Presenting Issues Identified	Dr. David Serur
10:15	Patient and Community Assessment Results	CHAP Team
10:30	Break	
10:40	Discussing and Prioritizing Issues	All Participants
12:00	Lunch	
12:30	Overview of White House Transplant Summit Project	Dr. Amy Waterman
12:40	Developing a Roundtable Action Plan	All Participants
2:00	Break	
2:10	Finalizing Action Plans for Pilot Project(s)	All Participants
2:50	Closing Remarks	Dr. Barry Smith
3:00	Adjourn	



Jack J. Dreyfus Center for Health Action and Policy

Maurice R. and Corinne P. Greenberg Center for Integrative Healthcare

Friday, December 9, 2016 from 8:30am to 3pm (619 West 54th Street, 4th Fl., New York, NY 10019)

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Transplant Roundtable Participant Biosketches



Lisa Baxter is President and Founder of Blessed Kidney Connections, which she started in 2010. She found out that there were many people unaware of the seriousness of kidney disease and what trials and tribulations dialysis patients go through. After being diagnosed with Polycystic Kidney Disease in 1995, she decided to write a book "Through the Eyes of a Dialysis Patient". She began receiving dialysis in February 2004, which inspired her to become an advocate for patients and family members. A DVD "Life on Dialysis: The Lisa Baxter Story" was made in 2009. The disease has not stopped her from living life to the fullest. She is employed full-time as a Family Worker for Head Start/Daycare program in Brooklyn and Queens in New York City. She continues to help those who are in need. Lisa enjoys spending time with family, acting, singing, swimming, traveling, bowling and exercise. She recently received a kidney transplant.



Natalie Ruth Benavides, MS joined the LiveOnNY as the Director of Hospital Services in July 2012. In 2016, her role expanded to include Family Services. She has nearly 15 years of nonprofit development experience with a particular specialization in the field of organ, eye and tissue donation. Previous to joining NYODN, Natalie was the Executive Director of Donate Life Maryland; the organization awarded the state contract to provide and maintain an official donor registry for the State of Maryland. She was both a Hospital Services Specialist and Donation Specialist for Washington Regional Transplant Community, the federally designated organ procurement organization for the Washington, DC metropolitan area. In addition to her work on a local level, she has contributed to national forums established to respond to the ever-increasing need for transplantable organs. She was elected to Faculty for Donate Life America and served a term of three years. Likewise, she was appointed the State Team Development Chair for the Donor Designation Collaborative. In both 2014 and 2016, Natalie was asked to serve as a Producer for the Association of Organ Procurement Association's annual meeting. She was awarded second place in 2015 for an abstract detailing the results of implementing a new, innovative staffing design for Hospital Services. Her work, extending beyond the community of donation and transplantation, includes serving as Director of Corporate Relations for the American Heart Association in Baltimore, MD and was a member of the H*Works Team of the Advisory Board Company. She is a graduate of The American University and has a Master of Science in Nonprofit Leadership from Fordham University. Natalie is also an altruistic kidney donor.



Adam W. Bingaman, MD, PhD is the Director of Abdominal Organ Transplantation, Live Donor Kidney Transplant Program, Renal Transplant Research Program and a Kidney and Pancreas Transplant Surgeon. As the Director of Abdominal Organ Transplantation at Texas Transplant Institute at Methodist Specialty and Transplant Hospital in San Antonio, Dr. Adam Bingaman heads up some of the best known and most-preferred programs, not only in San Antonio and South Texas, but also nationally, in the case of the Live Donor Kidney Transplant Program.

Dr. Bingaman graduated from Cornell University with a Bachelor of Arts in biochemistry, received his medical degree from Boston University School of Medicine and then went on to complete his general surgery residency training at Emory University in Atlanta, Georgia. During his residency he earned a doctorate in immunology from Emory University Graduate School of Biological Sciences, where his research focused on how the immune system rejects transplanted tissues. He then went on to complete his fellowship training in kidney and pancreas transplantation surgery at the University of Maryland.

Prior to joining Texas Transplant Institute, Dr. Bingaman was Assistant Professor of Surgery at Medical College of Georgia, and University of Texas Health Sciences Center, San Antonio. He is board certified by the American Board of Surgery, is a member of the American College of Surgeons, and has published extensively in the field of transplantation immunology.



Councilwoman Jane Bonner is a longtime advocate for the people of northeastern Brookhaven, where she was elected to the Town Council in 2007. Prior to her election, she served as the Legislative Aide to former Suffolk County Legislator Dan Losquadro. Jane has also served as president of the Rocky Point Civic Association, and during her tenure, helped residents of the area by solving the problems they were experiencing in their neighborhoods. As a constituent services liaison she helped community members navigate their way through town, county, state and federal agencies.

As the past president of the Rocky Point Revitalization and Beautification Committee, her vision for a better future through responsible planning continues to have a positive effect on the community. She secured more than a half million dollars in grant money for the Rocky Point downtown business corridor, making Main Street more attractive and improving the quality of life for all residents.

Today, Councilwoman Bonner is a leading voice for Brookhaven residents, small business owners, seniors, children and the environment. Her actions on behalf of the constituents that she serves make a positive impact on the community. The Route 25A Corridor Study, which helped to achieve smart growth development all along the district's busiest road, has saved small business mom and pops from big box stores and overdevelopment. She rescued the Nature Center at Cedar Beach from demolition and created an educational environmental learning center for children, and preserved hundreds of acres of land as open space to be enjoyed for generations to come.



Marian B. Charlton, RN, SRN, CCTC received her degree in Nursing from the Barking and Havering School of Nursing in London, England. She completed an ENB Certification in Neurosciences and is certified as a Certified Clinical Transplant Coordinator (CCTC) since 1999. Marian began her career in Transplant at NewYork-Presbyterian Hospital/Weill Cornell Medical Center (NYPWC) in 1988 as a Staff Nurse on the inpatient Transplant Unit. She transitioned to the role of Transplant Coordinator in 1998 and held various roles such as Post Kidney and Pancreas Transplant Coordinator, Liver Transplant Coordinator and Living Donor Transplant Coordinator. Currently, Marian is the Chief Clinical Transplant Coordinator at NYPWC's Kidney and Pancreas Transplant Program. In this role, she is the Clinical Manager for both the Living Donor and Kidney Paired Donation (KPD) Programs. Marian has been instrumental in program development, continuous improvement and increasing Living Donation transplants at NYPWC.

Marian's primary focus and passion is Living Kidney Donation. She gained national recognition as Co-chair for several NATCO sponsored meetings: Transplant Institute 2005, Annual Meeting 2007 and Donation & Transplantation Academy 2012 to present. She was the NATCO representative at the Living Kidney Donor Follow-up Consensus Conference in 2011 and participated in the Kidney Paired Donation Consensus Conference in 2012.

Marian has been actively involved in the American Society of Transplantation's (AST) Living Donation Community of Practice (LDCOP), working with the Advocate subgroup to develop best practices for the Donor Advocate role within the Transplant Community. Marian was voted to AST LDCOP in the role of Committee Member-At-Large.



Deana Clapper, APRN-BC, MSN, CCRN, CPTC, CTBS is the Senior Director of Clinical Operations within Tennessee Donor Services (TDS), a busy organ, eye, and tissue recovery organization that completes on average 250 organ donor and 1800 tissue and eye donor recoveries annually. She has worked with TDS for 15 years, initially as an Organ Recovery Coordinator, spending several years as the Director of Quality, and for the past four years, has overseen clinical services. She began her career in healthcare as a critical care nurse, obtaining a Master's in Nursing from Vanderbilt University in 1997. Working as an Acute Care Nurse Practitioner within Trauma Services at Vanderbilt Medical Center allowed her to become familiar with the donation side of the process. However, not until she joined TDS, a subsidiary of Dialysis Clinics, Inc., did she begin to understand the complexities unique to transplantation and access to life saving organs.



Tom D'Antonio is a small business owner, happily married to wife Cheryl for 27 years (who while dating, was his first kidney donor in 1988), and father of Jackson. He lives in the quintessential Norman Rockwellesque village of Northport NY on LI's North Shore, is an avid sailor, a proud soccer coach, and a restorer of old cars (especially British cars). He also holds a NY State certification as an Emergency Medical Technician and has been a volunteer with Huntington Community Rescue for 17 years.

Tom counts among the many miracles in his life, in addition to his wife and son, the 6 heroic people who gave him life again through their commitment to something bigger than themselves: Jon Desjardins, a brother EMT who happened to be on the same commuter train as him and performed life saving CPR after he suffered an acute thrombosis which stopped his heart and respirations for 12-14 minutes, on 10-17-2012; Carla D'Antonio Minervini (his sister), who on 6/7/2002 was his 2nd kidney donor; the parents of a 15 year old young girl who was his pancreas donor on 4/15/1999; his wife Cheryl who, as mentioned earlier was his first donor in 1988; and his latest hero, Jane Bonner, who gave him a kidney on 4/26/16.

Tom also is compelled to mention the 8-12 friends who all stepped forward and were tested for this last transplant, including his son Jackson, and the literally dozens of doctors, nurses and various technicians from North Carolina to NY, who are all committed to a cause greater than themselves, not the least of whom is Dr. David Serur, his brother from another mother. For these blessings in his life, he gives thanks daily.



Thomas Hugh Feeley, PhD is Professor of Communication at University at Buffalo, The State University of New York. He studies public communication campaigns and behavioral interventions to promote organ and tissue donation with an emphasis in New York State. In addition, he is interested in decision-making in relation to joining the organ and tissue donation registry. His research has been funded since 2003 by Health Resources Services Administration (HRSA; Division of Transplantation). Professor Feeley has authored over 20 journal articles and book chapters on the topic of deceased and living organ donation.



Kevin J. Fowler is a healthcare executive with over 30 years of Life Sciences experience in pharmaceutical commercial and R&D organizations. His career has encompassed a breadth and depth of skills and experiences. During his career, he has demonstrated leadership in sales management, training, public affairs, global marketing, patient advocacy, and patient marketing. He formed his own patient advocacy and patient engagement consulting business in 2014, "The Voice of the Patient, Inc." Based upon his personal experiences of having a pre-emptive kidney transplant in 2004, he has a deep passion for patient advocacy and patient engagement. Kevin brings the patient voice to several organizations as a volunteer: Kidney Health Initiative, Patient Family Partnership Council; National Kidney Foundation, Kidney Advocacy Committee; American Society of Transplantation, Patient Advisory Group; Board of Directors, American Association of Kidney Patients; Kidney Research Institute, Patient Advisory



Mary L. Ganikos, PhD received her doctorate in mental health counseling with a specialization in gerontology from the University of Florida in 1977. She started her government career in 1981 at the National Institute of Mental Health, leaving there for the National Institute of Alcohol Abuse and Alcoholism in 1984. In 1990, she accepted a position in the Division of Transplantation (DoT), Health Resources and Services Administration, where she serves today as the Lead for the Donation Education Team.

In this capacity, Dr. Ganikos has developed many varied strategies and programs with the ultimate goal of increasing organ, eye, and tissue donation. As examples, she coordinated the 1991 Surgeon General's Workshop on Increasing Organ Donation; started and coordinated the first annual National Donor Recognition Ceremony in Washington, DC; oversaw the creation of DoT's first research grant program, and three subsequent grant programs; and worked closely with the office of former HHS Secretary Tommy Thompson's to plan and implement his national donation campaign. Dr. Ganikos also coached and oversaw the production of two documentaries nationally broadcast on PBS, one of which won a 2003 national Emmy Award. She initiated and served as the project officer for the 2005 and 2012 nationally representative surveys conducted for HRSA by the Gallup Organization to measure the American public's organ donation attitudes and practices. Through a multi-year collaborative effort with CDC, Dr. Ganikos provided consultation and coaching to screenwriters of medically oriented television programs, such as *Grey's Anatomy* and *Private Practice*, to promote accuracy in their donation and transplantation storylines. In recent years, she has steered HRSA's public outreach program into the social media arena.



Kimberly Jacob Arriola, PhD, MPH is a Professor in the Rollins School of Public Health of Emory University in the Department of Behavioral Sciences and Health Education. She earned a MA in 1996 and a PhD in 1998 from Northeastern University (both in Social Psychology), and she earned an MPH in 2001 from Emory University (in Epidemiology). All of her work focuses on studying social and behavioral factors that impact the health of marginalized populations and communities of color. She has two general lines of research. First she has led the development, implementation, and evaluation of culturally sensitive interventions to improve public commitment to organ and tissue donation among African Americans and interventions that improve access to transplantation among African American end stage renal disease patients. Second, she has led the implementation and evaluation of environmental and policy change interventions that improve access to cancer screening and treatment services among those who are underserved and underinsured. She also serves as Associate Dean for Academic Affairs for the Rollins School of Public Health and teaches in both the Masters and Doctoral programs in her department.



Sandip Kapur, MD, FACS is Chief of Transplant Surgery and Director of Kidney and Pancreas Transplant programs at NewYork-Presbyterian Hospital/Weill Cornell Medical Center. He is a Professor of Surgery at Weill Cornell Medical College and an Attending Surgeon at NY-Presbyterian Hospital/Weill Cornell Medical Center. In February 2010, Dr. Kapur was named the G. Tom Shires, M.D. Faculty Scholar in Surgery in recognition of his outstanding commitment to clinical surgery, research, and education.

An internationally recognized expert in pioneering transplant techniques, Dr. Kapur specializes in adult and pediatric kidney transplantation and pancreas transplantation. Dr. Kapur heads the oldest kidney transplant program in New York State, and one of the highest volume programs in the country. He is a nationally recognized pioneer in developing innovative strategies that allow for successful transplantation in situations where transplants might be contraindicated at most other centers. These include crossmatch and blood type (ABO) incompatible programs, donor exchange for live kidney donation, and facilitating transplantation in older individuals.

Dr. Kapur earned his undergraduate degree from Fordham. He earned his MD in 1990 from Cornell University Medical College, and completed his internship and residency in general surgery at NY-Presbyterian/Weill Cornell Medical Center in 1996. He was a research fellow from 1993-1994 in Transplant Immunology at Weill Cornell Medical College, and from 1996-1998, he completed a fellowship in Multi-Organ Transplantation at the University of Pittsburgh Medical Center Thomas E. Starzl Transplantation Institute.



Gerard Jerry Kassar has served as Chief of Staff to State Senator Martin Golden of Brooklyn since 2004. Prior to serving with the Senator, Mr. Kassar held a number of senior staff positions in the State Assembly including management of all Regional Service operations for the Assembly Minority and as a Senior Advisor to the Assembly Minority Leader. He is active in politics, holding the dual positions of Chairman of the Kings County Conservative Party and Vice Chairman of the NYS Conservative Party. Mr. Kassar is a former President of the Dyker Heights Civic Association and Member of the Board of Directors of the Victory Memorial Hospital, which closed several years ago. He has written a weekly column for several Brooklyn newspapers entitled "Common Sense" since 1988. He is a graduate of Pace University with a BBA in Accounting.

Mr. Kassar was first diagnosed with Kidney Disease in January of 2009. He was placed on the Transplant list in April of 2016 and began Dialysis in May of 2016.



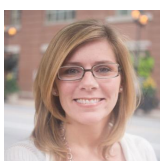
Dianne LaPointe Rudow, DNP is an Associate Professor, Department of Population Health Science and Policy, Director of the Zweig Family Center for Living Donation at the Recanati Miller Transplant Institute at Mount Sinai Hospital. She has an extensive career in solid organ transplantation and joined the Mount Sinai Team in April 2010 to develop and direct The Zweig Family Center for Living Donation where she leads a comprehensive care team for liver and kidney donors, making it the first of its kind to provide innovative expertise in the medical, surgical, and psychological health before and after live organ donation.

Dr. LaPointe Rudow has published and presented on live donor advocacy both nationally and internationally. Additionally she has served on many boards and committees on transplantation. In May of 2013 she was honored at the American Transplant Congress in Seattle Washington by receiving the American Society of Transplantation's (AST) Clinician of Distinction Award.

Over the years Dr. LaPointe Rudow has been on the Board of Directors of AST, President of NATCO, and served multiple positions within UNOS including Board of Directors of UNOS, Live Donor Committee, and Membership and Professional Standards committee and the Disease Transmission Advisory Council (DTAC). She is currently the Secretary of UNOS.



Christa Lawson, RN, BSN is the Transplant Coordinator at Reach Kidney Care in Nashville, TN. She works primarily with CKD patients that Reach serves in the Middle TN community, providing transplant education and facilitates early referral and pre-emptive transplant whenever possible. She also works with dialysis patients in the Music City Kidney Care Alliance ESCO promoting transplant. Christa was previously a kidney transplant coordinator at Vanderbilt University Medical Center for 17 years.



Catina O'Leary, PhD, LMSW is President and CEO of Health Literacy Media (HLM), a nonprofit health communications company located in downtown Saint Louis. Under her direction, HLM's service network has expanded to include some of the largest employers in Missouri, including pharmaceutical companies, hospital systems, business coalitions and community-based organizations. These services provide training for more than 3,600 health care providers in clear health communication and the translating of over 120-health education and marketing documents into plain language that community members can understand and use.

Before her appointment as CEO of HLM, Dr. O'Leary oversaw community-engaged research projects at Washington University School of Medicine locally, nationally and internally. She is a founding Board member of and current President of the Board of Directors for Magdalene St. Louis, an organization focused on supporting women who have survived lives of abuse, prostitution, trafficking, and addiction by providing a community where they can recover and rebuild their lives. She is a member of the St. Louis Regional Health Commission Community Advisory Board and the RHC Alive and Well St. Louis Executive Steering Committee. In her role as President of HLM, O'Leary participates as a member of the National Academy of Sciences Roundtable on Health Literacy.

Dr. O'Leary earned her BA in psychology from the University of Mississippi and MSW and PhD in social work from the George Warren Brown School of Social Work at Washington University.



Rachel Elizabeth Patzer, PhD, MPH is an assistant professor of surgery and epidemiology at Emory University School of Medicine and the Director of Health Services Research at Emory Transplant Center in Atlanta, GA. Her research focuses on quality and equitability in access, health services, and outcomes of transplantation. Much of her research focuses on improving access to kidney transplantation, including studying the effectiveness of multicomponent educational interventions to improve transplant access for dialysis patients, identification and measurement of transplant quality measures for dialysis facilities, and the development of new technology to improve communication between dialysis facility providers, transplant centers, and patients.



Glenda Payne, MS, RN, CNN began her experience in nephrology as a patient's wife in the early days of transplantation. Her early clinical experience as a registered nurse included work in peritoneal dialysis, renal transplantation, and later as a renal clinical nurse specialist and a clinical research nurse.

Later work experience included the Texas Department of Health as a health facility surveyor and the Centers for Medicare & Medicaid Services where she participated in various workgroups to advise and assist in making changes to the CMS survey process, the ESRD Conditions of Coverage, the Interpretive Guidance, and for 22 years was a member of the core faculty for CMS' ESRD surveyor training. While working for the state and CMS, Glenda also participated in and supervised surveys of organ transplant programs.

In 2011, she began work as the Director of Clinical Services for Nephrology Clinical Solutions, a consulting group that provides education, training and clinical solutions for clients in the nephrology community.

Glenda is certified as a Nephrology Nurse, and active at the local, regional, and national levels of the American Nephrology Nurses' Association, including having served as President of ANNA for 2012-13.



Mendy Reiner was born, raised and currently lives in New York. In 2006 after seeing a friend suffer on dialysis, he set out to find a solution. In the process he found that there are many people willing to donate a kidney, which subsequently led to his founding of Renewal, a non-profit organization dedicated to facilitating living kidney transplants. Mendy has made it his mission to help anyone get a second (or third) chance at life. From its humble beginnings, Renewal has grown to become one of the foremost organizations in the nation specializing in living kidney donations. In addition to being the Founder of Renewal, he serves the organization on a volunteer basis as Chairman of the Board. His goal is to bring the average wait time down from 5-7 years to 6-8 months.



Gregory Lyons Segal is the co-founder of ORGANIZE, a non-profit modernizing the organ donation system through the introduction of new technologies and data-driven policies.

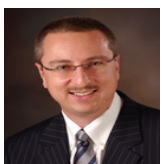
ORGANIZE has been recognized in the Inc Magazine 35 Under 35 List, the Forbes 30 Under 30 List, and Oprah's Inaugural List of 100 Super Soul Influencers. ORGANIZE was awarded the \$1 million 1st Prize in the 2014 Verizon Powerful Answers Award, the Inaugural Stanford MedX Health Care Design Award, the Tribeca Disruptive Innovation Award, the Classy Award, and an Innovator in Residence Position in the Office of the Secretary of the US Department of Health and Human Services.

Greg graduated from Duke University in 2006 with a BA in Psychology and began his career in education technology venture investing at Rethink Education. He currently serves as Board Member at Bayes Impact and The Philanthropy Workshop and was also once the Starbucks Customer of the Week at the Ventura Boulevard location in Encino, CA.



David Serur, MD came to NewYork-Presbyterian/Weill Cornell in 1991 with an interest in clinical transplantation and has been Medical Director of the kidney transplant program since 2007. For the past 15 years he has been supervising the evaluations of kidney donors at Cornell, which performs 150 living donations annually. Research interests have included pharmaceutical industry supported studies of new transplant medications as well as investigator-initiated studies. Dr. Serur was one of the earliest proponents of offering kidney transplantation to HIV patients on dialysis; something that many thought was too risky but is now routinely done. Recent interests have been in studying non-directed donors and donors within paired exchange. He serves on the editorial board of the journals *Transplantation* and *Progress in Transplantation* and served on the medical boards of the NY Organ Donor Network and the Manhattan chapter of TRIO, the transplant recipient organization. Being involved in kidney paired exchange since its inception at Cornell in 2008, Dr. Serur has volunteered as Medical Director of the National Kidney Registry, the largest paired exchange program in the world.

Dr. Serur serves on the executive committee of the AST Living Donor Community of Practice and has recently chaired committees in national consensus conferences: the KPD consensus conference and Best Practices in Living Donation conference. Currently he is developing an online educational tool kit for living donor transplantation. In March 2016 he visited the White House to advise the White House National Economics Council on ways to promote organ donation and remove disincentives from live donors and then joined the White House Organ Summit in June 2016.



Joe Sinacore is the Director of Education & Development at National Kidney Registry (NKR), the world's most successful paired kidney exchange program. To date his work at the NKR has helped facilitate transplants for nearly 2000 patients. He's been involved for the past nine years since its conception in late 2007, and had previously worked with NKR's founder & CEO, Garet Hil, since 1993. Joe speaks frequently at many public events and medical conferences around the country, regarding the vital work of the NKR. He is often interviewed and quoted in many news stories about the program.

Joe is intimately involved in all day to day business activities including outreach and education, business planning, new center on-boarding, kidney swap management, logistics, advanced matching strategies, data compliance, research, systems testing, website management, public speaking and social media. Joe works with the brightest doctors, nurses and scientists in the field of kidney transplant. He has collaborated with these medical professionals on many published research papers and industry presentations.

He is passionate about paired kidney exchange and continually motivated by the dire need to help facilitate transplants for the over 90,000 in need of a good kidney match.



Barry H. Smith, MD, PhD is the President and CEO of The Rogosin Institute and Director of its Dreyfus Health Foundation division. He is Professor of Clinical Surgery at Weill-Cornell Medical College and Attending Physician at the NewYork-Presbyterian/Weill Cornell Medical Center. He graduated from Harvard College in 1965; received his PhD in Biology/Neurobiology from the Massachusetts Institute of Technology (MIT) in 1968; and his MD from Cornell University Medical College in 1972, with residency training at both New York Hospital and Massachusetts General Hospital and five years at the National Institutes of Health as Deputy Chief of Surgical Neurology.

Dr. Smith is involved in patient care and basic and clinical research in diabetes and cancer. He has worked for more than twenty years working to promote problem-solving skills among health professionals and medical and nursing students (more than 20,000) in over 30 countries around the world. He is the author of more than 100 scientific and clinical papers, Co-Editor of Elsevier's *Encyclopedia of Neuroscience*, and an Editor of *Problem Solving for Better Health: A Global Perspective*.



Manikkam (Suthan) Suthanthiran, MD was born in Madras, India. He received his medical degree from the University of Madras and completed his Internal Medicine Residency training at Wayne State University, Detroit, Michigan. He was a Nephrology Fellow at the Peter Bent Brigham Hospital and Harvard Medical School, Boston, Massachusetts. Dr. Suthanthiran holds the Stanton Griffis Distinguished Professorship in Medicine, and Professorships in Biochemistry and Surgery in Medicine at Cornell University Medical College. He is the Founding Chairman of the Department of Transplantation Medicine, and Chief of Nephrology and Hypertension at The NewYork-Presbyterian Hospital/Weill Cornell Medical Center. Dr. Suthanthiran serves as the Co-Chair of the Executive Transplantation Council of the Multi-Organ Program of Columbia and Cornell, NewYork-Presbyterian Hospital.

Dr. Suthanthiran's research is in the area of Transplantation Immunobiology. His laboratory investigates T-Cell signaling, mechanism of action of immunosuppressants and the immunology and molecular biology of allograft rejection. He serves as the Director of Center for Islet Transplantation at Cornell.



Amy D. Waterman, MD, PhD is a Social Psychologist and Associate Professor in Residence in the University of California Los Angeles (UCLA) Division of Nephrology. Dr. Waterman is driven by three beliefs. First, transplant-eligible kidney patients deserve to make informed choices about their treatment options, especially deceased and living donor transplantation. Second, there are many generous people who might become deceased and living kidney donors, but they need to learn what donation involves. Third, if we all work together – kidney patients, their families and communities, and kidney healthcare professionals – our collaborative efforts can reduce the national kidney donor shortage and increase the number of people living longer with the benefit of kidney transplants.

Her Transplant Research and Education Center (TREC) at UCLA focuses on understanding the critical, modifiable patient, provider and system barriers affecting deceased and living donor kidney transplant rates and designing interventions to overcome them. Dr. Waterman's research laboratory examines how best to expand access to transplant, reduce racial disparities in transplant, ensure informed decision-making, ensure transplant adherence, promote paired donation, and increase living donation rates.

Dr. Waterman's research incorporates many components of clinical and translational research including patient-oriented research, clinical trials, behavioral studies, development of new educational technologies, cost-effectiveness analyses, outcomes and health services research, and implementation of best practices. TREC focuses on translating the findings from effective clinical trials into everyday practice through collaboration with healthcare providers, national transplant leaders and healthcare policymakers.

Transplant Roundtable Key Issues

Education:

- There is a lack of adequate public education regarding organ donation
 - What transplantation can achieve for individual patients?
 - The significance of the benefit that deceased organ donors can provide to those in need of a transplant.
 - Education about who can be a living donor while alive.
 - Strategies for effective dissemination of existing interventions.
 - NY is # 50 in terms of organ transplant rate. Correlates with problems in our public education system, as well as in the NY State Department of Health.
 - Organ donation needs to have national awareness programs, similar to those for cancer and heart disease.
 - How can we better leverage already available organ donation-related resources, services, organizations, and leaders more effectively on a national level?
 - How do we combat prevalent myths and misinformation circulating in society that preclude positive donation decisions?
- Need for more patient education
 - Nationally mandated competencies would be required of all dialysis facilities for the education of their patients.
 - More education about transplant necessary at early stages of CKD.
- Need for more donor education
 - More education regarding lifelong changes, if any, the donor will need to make.
 - The true risks to living organ donors.
- Provider education/training needs
 - What opportunities exist or should exist in the realm of healthcare provider training and education to prepare critical care professionals for their role in the facilitation of deceased donation.
- Need for health literate communication/education at all levels
 - Individuals awaiting transplant, through the process, and their families, are challenged with understanding variety of complex health messages in a high-risk situation.
 - Need careful thought about where (location) information is provided, by whom, at what point of care, how frequently, what else is going on when information is shared, and many other similar, seemingly simple questions.
 - Need more education materials in languages other than English.

Role of Healthcare Institutions:

- The importance of hospital culture and provider engagement to preserve the deceased donation opportunity for families.
- How to increase the collaboration and support of area hospitals in the facilitation of

deceased donation?

- Quality metrics for dialysis facilities, including better measurement of transplant education and referral for transplant evaluation.
- Quality metrics for transplant centers to ensure centers are held accountable for entire ESRD population eligible for transplant.
- What are the right metrics in measuring success and progress in the field of organ allocation and transplantation?
- Integrate patient voice in risk-benefit conversations on extended criteria kidneys, quality measures, and situations discussing the trade off between benefits and risks.

Increasing Donor Population

- How to increase the number of living kidney donors?
 - How to increase the number of pre-emptive kidney transplants?
 - How to promote organ donation in our communities, including living kidney donors?
- What measures has New York taken to increase the percentage of its population registered as organ donors?
 - What future opportunities exist to improve the status of the state's donor registry?
- Creating ways to spread the visibility and raise awareness of the shared donor network.
- There is a need to increase the number and proportion of ethnic/racial minorities who consent to donation through their respective state registry and through communication with next-of-kin.
- Improve efforts to register one's organ donation consent in both online (registry, OPO) and offline formats (DMV, other formats).
 - Expand the use of new tools to facilitate donation
- Utilizing social media to increase organ donation.
- Increase surgical capacity to increase Kidney Paired Donation transplants by 100-200 annually.
- Encourage transplant professionals to consider becoming kidney donors (leadership by example).
- Need for more opportunities for finding local connections for donors/recipients.
- How to reduce the number of unused deceased donor kidneys?

Support, Preparation, Recovery for Donors

- Accurate preparation regarding recovery for the donor.
- How medical test results are disseminated to the donor?
- Create a donor buddy system made up of previous donors who volunteer to help support donors.
- More involvement in the process for family members, especially spouses.
- Integrated Patient Engagement Strategy: understanding your kidney function first, pre-transplant education on all renal replacement options, and post-transplant wellness orientation.
- Improving follow-up for living donors, including treating the organ donor as a true VIP, covering all costs for living donors.

Removing Patient Related Barriers to Care:

- The number of Americans who have no or insufficient health care coverage.
- Working to eliminate transplant center barriers for patients and variation in pre-transplant evaluation processes (e.g. requirements for fundraising, dental exams, etc).
- What barriers seem insurmountable in the field of organ donation and why do we think they are so fixed? How can we think differently about overcoming these barriers?
- Racial/socio-economic disparities in access to renal transplant are widely pervasive.
 - There is a need for interventions that exist at multiple levels of the social ecology (i.e., individual, interpersonal, community, policy, societal) to address these disparities.

Policy Changes:

- More research into what public policy or economic changes should be made in the field of organ donation that would make the most difference?
- How to align financial and regulatory incentives of referring providers such as dialysis facilities and CKD clinics with transplant centers?
- Policy changes that make living donation easier.