

PAUL T. CONWAY

PROFESSIONAL SUMMARY

National patient advocate and Chair of Policy and Global Affairs for the American Association of Kidney Patients, the oldest and largest, independent kidney patient advocacy organization in the United States. Experienced policy and communications practitioner with extensive background managing research agendas, implementation of White House and gubernatorial cross-Cabinet policy and management initiatives, Congressional legislation and budget re-authorizations and Federal and state government agencies. Operational expertise includes Federal continuity of government and security clearance programs, policy issue sequencing, human capital assessment and talent alignment, annual budget and performance metrics management and coordination of responses to external oversight and internal agency Office of Inspector General investigations. Strategic communications experience includes stakeholder and surrogate coordination, crisis and reputation management, policy initiative rollouts, editorial board presentations, press briefings with scope including National Press Club to Air Force One, social media and earned media program integration and live national television and radio guest and surrogate appearances.

PROFESSIONAL EXPERIENCE

PRESIDENT, *Conway Strategies Global*, Falls Church, Virginia, November 2012 to present; April 2009 through July 2010.

PRESIDENT, *Generation Opportunity*, Arlington, Virginia, August 2010 through November 2012.

ACTING FEDERAL COORDINATOR AND CHIEF OF STAFF, United States Department of Homeland Security, Office of Gulf Coast Rebuilding, Major General Douglas O'Dell (USMC, ret.), Washington, D.C. April 2007 to April 2009. **DHS SENIOR TRANSITION OFFICER, BUSH/OBAMA PRESIDENTIAL TRANSITION**, November 2008 to April 2009.

CHIEF OF STAFF, United States Department of Labor, Secretary Elaine L. Chao, Washington, D.C., August 2005 to April, 2007.

CHIEF OF STAFF, United States Office of Personnel Management, Director Kay Coles James, Washington, D.C. July 2001 through January 2005. **CHAIR**, Senior Executive Service Performance Review Boards and Executive Review Boards, 2002-2005. **SENIOR ADVISOR TO THE ACTING DIRECTOR**, February 2005 to June 2005.

DEPUTY DIRECTOR, The Heritage Foundation, The Citizenship Project, Virginia, June 1999 through June 2001.

ACTING DEPUTY EXECUTIVE DIRECTOR, National Gambling Impact Study Commission, Office of the Chair, Washington, D.C., June 1998 through August 1998.

ASSOCIATE DEAN AND ASSISTANT PROFESSOR OF POLITICS, *Regent University School of Government, Virginia Beach, Virginia, December 1998 to June 1999*. **SENIOR RESEARCH FELLOW & DIRECTOR OF COMMUNICATIONS**, *July 1996 through November 1998*.

DEPUTY SECRETARY OF HEALTH AND HUMAN RESOURCES, *Office of the Governor, Governor George Allen, Richmond, Virginia, June 1994 through June 1996*. **CHAIR, SECRETARY'S COUNCIL ON AUDIT AND CONTROL**, *May 1995 through June 1996*.

DIRECTOR OF COMMUNICATIONS AND RESEARCH CONSULTANT, *Drug Control Policy Group, Sparta Corporation, Bethesda, Maryland, January 1993 through May 1994*.

SPECIAL ASSISTANT AND REGIONAL LIAISON, *Executive Office of the President, Office of National Drug Control Policy (ONDCP), designated liaison for Federal New England and Midwest Regions, April 1992 through January 1993*.

COMMUNICATIONS CONSULTANT, *Arlington, Virginia, April 1991 through March 1992*.

EXECUTIVE VICE PRESIDENT, *David Welch Associates, Inc., Arlington, Virginia, February 1990 through April 1991*. **DIRECTOR OF OPERATIONS**, *April 1989 through January 1990*.

CONFIDENTIAL ASSISTANT, *Office of the Secretary, United States Department of Education (DOE), Washington, D.C., August 1988 through March 1989*.

EDUCATION AND PROFESSIONAL TRAINING

PROGRAM FOR SENIOR EXECUTIVES IN NATIONAL AND INTERNATIONAL SECURITY, *Harvard University, John F. Kennedy School of Government, Cambridge, Massachusetts, August, 2003*.

BACHELOR OF ARTS DEGREE, *Political Science, University of Maine, Orono, Maine, 1987, Member, Senior Skull Honor Society*.

RECENT PUBLICATIONS

CO-AUTHOR: Fowler KJ, Conway PT. The New HHS Kidney Innovation Accelerator, When Innovation Stalls, HHS Says Floor it! *Clinical Journal of the American Society of Nephrology*; November 2018, 13 (11) 1747-1749.

AUTHOR: Conway PT. Trust Patient Insights at both the Individual and Local Level, *Clinical Journal of the American Society of Nephrology*; January 2018, 13 (1) 1-2.

CO-AUTHOR: Rosner MH, Lew SQ, Conway PT, Ehrlich J, Jarrin R, Patel UD, Rheuban K, Robey RB, Sikka N, Wallace E, Brophy P and Sloand S. Perspectives from the Kidney

Health Initiative on Advancing Technologies to Facilitate Remote Monitoring of Patient Self-Care in RRT. *Clinical Journal of the American Society of Nephrology*; November 2017, 12 (11) 1900-1909.

CONTRIBUTOR, *Kidney Failure, A Smarter Giving Guide*, The Milken Institute, March, 2017.

SELECT PROFESSIONAL AFFILIATIONS

STEERING COMMITTEE, *American Society of Nephrology 2019 Kidney Week, April 2018 through November 2019*

APPOINTED CHAIR, *Patient Engagement Advisory Committee, Office of the Commissioner, U.S. Food and Drug Administration, March 2017 – present.*

APPOINTED MEMBER, *External Evaluation Panel (EEP), Kidney Precision Medicine Project (KPMP), U.S. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, January 2018 – present.*

APPOINTED MEMBER, *Presidential Rank Review Board, U.S. Office of Personnel Management, (for evaluation and recommendation of Federal Senior Executive Service personnel for recognition by President Donald Trump), April 2018.*

APPOINTED MEMBER, *Presidential Rank Review Board, U.S. Office of Personnel Management, (for evaluation and recommendation of Federal Senior Executive Service personnel for recognition by President Donald Trump), April 2017, April 2017.*

APPOINTED MEMBER, *Kidney Committee, United Network for Organ Sharing (UNOS), 2017 – present.*

PATIENT VOICE EDITOR, *Clinical Journal of the American Society of Nephrology (CJASN), November 2017 – present.*

CHAIR, *Patient Access to Pain Relief (PAPR) National Coalition, 2015 – present.*

CHAIR, *Center for Medicare and Medicaid Services (CMS) Technical Evaluation Panels for Dialysis Facility Quality Ratings & Patient Reported Outcomes 2015 – 2017.*

MEMBER, *Kidney Disease Scientific Advisory Group, The Milken Institute for Scientific Philanthropy 2016 - 2017.*

MEMBER, *Board of Directors, Quality Insights Renal Network 5, CMS End Stage Renal Disease Network Contract Administrator, 2012 - 2018.*

NATIONAL BOARD MEMBER, *Kidney Health Initiative, (a collaboration of the U.S. Food and Drug Administration and the American Society of Nephrology), 2015 – present.*

NATIONAL PATIENT ADVISORY BOARD MEMBER, *Center for Dialysis Innovation (CDI), University of Washington, 2017 - present.*

APPOINTED MEMBER, *Clinical Trial Transformation Initiative (CTTI), (a collaboration of the U.S. Food and Drug Administration and Duke University), Duke University, 2016 – 2018.*

APPOINTED MEMBER, *Commonwealth of Virginia, Board of Health Professions (Health Professional Licensing), 2010-2014.*

APPOINTED MEMBER, *Commonwealth of Virginia, Secure Commonwealth Panel (Homeland Security), 2010-2014.*

SELECT NATIONAL AND FEDERAL RECOGNITIONS

RECOGNITION, *Clinical Trials Transformation Initiative, Decentralized Clinical Trials, for contributions as a Project Team Member upon completion of “Legal, Regulatory, and Practical Considerations Affecting the Adoption of Decentralized Clinical Trials,” published September, 2018.*

PRESIDENT’S MEDAL, *American Society of Nephrology, top award of the world’s largest kidney professional medical society for superior communications and advocacy work before the United States Congress for kidney disease research, policy and funding, 2017.*

SECRETARY’S MERITORIOUS SERVICE MEDAL, *United States Department of Homeland Security, awarded by Secretary Michael Chertoff for exceptional individual leadership distinguished by achievements of marked significance to the long-term mission of DHS, 2009.*

SUPERIOR PERFORMANCE RECOGNITION (TWICE AWARDED), *United States Department of Homeland Security, for superior performance of duties as a Chief of Staff and Designated DHS Senior Transition Officer for the 2008 - 2009 Presidential Transition from President George W. Bush to President Barack Obama, March, 2009.*

SECRETARY’S AWARD FOR TEAM EXCELLENCE (TWICE AWARDED), *United States Department of Homeland Security, awarded by Secretary Michael Chertoff to staff teams under my leadership for The Transparency Initiative, web-based accountability tool utilized by U.S. Inspector Generals, Federal law enforcement and the media to track the expenditure of taxpayer funds across the Gulf Coast, November, 2008.*

EXEMPLARY ACTION AWARD, *United States Department of Homeland Security, presented by Major General Douglas O’Dell (USMC, Retired), Federal Coordinator for Gulf Coast Rebuilding for exemplary contributions to the mission of DHS, the Office of the Federal Coordinator and the citizens of the Gulf Coast, November, 2008.*

THEODORE ROOSEVELT ROUGH RIDER AWARD, *United States Office of Personnel Management, awarded by OPM Director Kay Coles James for duties and service in response to the terror attacks of September 11, 2001 and in support of the Global War on Terror, including the creation of the Transportation Safety Administration (TSA), the creation of the U.S. Department of Homeland Security (DHS) and the development of the Department of Defense National Security Personnel System (NSPS), January, 2005.*

OUTSTANDING PERFORMANCE AWARD, *Executive Office of the President, Office of National Drug Control Policy, awarded by ONDCP Director Robert Martinez for superior execution of duties as a Special Assistant and Regional Liaison to New England and the Midwest and for duties executed during the Presidential Transition of Presidents George H.W. Bush and William Jefferson Clinton, December, 1992.*

LETTER OF RECOGNITION AND PERFORMANCE AWARD, *United States Department of Education, awarded by the Office of the Secretary for outstanding service as a Confidential Assistant and for duties executed during the Presidential Transition of Presidents Ronald Reagan and George H.W. Bush, March, 1989.*

SELECT STATE HONORS AND RECOGNITIONS

LETTER OF APPRECIATION, *Commonwealth of Virginia, Office of the Governor, Secretary of Public Safety and Homeland Security, for contributions as a Member of the Secure Commonwealth Protection Panel's Subpanel on Recurrent Coastal Flooding and issues related to impacts on Virginia infrastructure and economy, September, 2015.*

HONORARY CITIZEN, STATE OF MISSISSIPPI, *awarded by Governor Haley Barbour, for services on behalf of the citizens and stakeholders of Mississippi related to recovery efforts for Hurricanes Katrina and Wilma, March, 2009.*

HONORARY CITIZEN, STATE OF ALABAMA, *awarded by Governor Bob Riley for efforts on behalf of the citizens and stakeholders of Alabama related to recovery efforts for Hurricanes Katrina and Wilma, March, 2009.*

HONORARY CITIZEN, STATE OF LOUISIANA, *awarded by Governor Bobby Jindal, for service on behalf of the citizens and stakeholders of Louisiana for recovery efforts related to Hurricanes Katrina and Wilma, January, 2009.*

HONORARY TEXAN, STATE OF TEXAS, *awarded by Governor Rick Perry for service on behalf of the citizens and stakeholders of Texas related to Hurricanes Ike, Gustav and Katrina, January, 2009.*

HONORARY CITIZEN, STATE OF WEST VIRGINIA, *awarded by Governor Joe Manchin III for service on behalf of victim families and the citizens and stakeholders of West Virginia during the 2006 Sago Mine Disaster and related support duties as the Chief of Staff of the United States Department of Labor, March, 2007.*

SELECT FEDERAL ENGAGEMENT & KIDNEY ADVOCACY ROLES

THE WHITE HOUSE:

- **STAKEHOLDER**, *White House Domestic Policy Council, discussion on patient pain management, opioids, OTC acetaminophen and complications stemming from the use nonsteroidal anti-inflammatory nonsteroidal anti-inflammatory drugs, May, 2018.*
- **INVITED PARTICIPANT**, *White House Summit on Organ Donation, participant in breakout sessions related to legal and regulatory barriers in transplantation policy, June, 2016.*
- **STAKEHOLDER**, *Office of Science and Technology Policy (OSTP), National Economic Council and the U.S. Department of Veterans Affairs, meeting and discussion regarding application development and utilization of gaming technology to better engage CKD and ESRD patients in nutritional programs and dietary information, January, 2016.*
- **STAKEHOLDER**, *Office of Science and Technology Policy (OSTP), discussion regarding the use of remote medical devices and technology to improve dialysis patient outcomes, November, 2015.*

DEPARTMENT OF HEALTH AND HUMAN SERVICES:

- **PARTICIPANT**, *Office of the Secretary, discussion on proposed Federal regulations on OTC extra strength acetaminophen and potential negative impact on kidney patients and kidney care, Washington, D.C., May, 2018.*
- **SPEAKER/VIDEO PATIENT TESTIMONIAL**, *in support of Federal agency efforts to spur innovation across the biologics, diagnostics and device space via the Kidney Innovation Fund, Washington, D.C., May 2018*
- **PARTICIPANT**, *Secretary Alex Azar meeting with Deputy Secretary Eric Hargan and HHS senior staff on KidneyX Innovation Fund (HHS), Washington, D.C., May, 2018.*
- **VIP PATIENT GUEST**, *Secretary Alex Azar public announcement on lowering the cost of prescription drugs, HHS Headquarters, Washington, D.C., May, 2018.*
- **PARTICIPANT**, *Secretary Alex Azar meeting, Office of the Secretary, discussion on high costs of prescription drugs, immunosuppressive drug costs and innovation in the field of medicine and kidney care, Washington, D.C., April, 2018.*

DEPARTMENT OF VETERANS AFFAIRS:

- **CONTRIBUTOR**, *Kidney Innovations Summit, February, 2017.*

CENTERS FOR DISEASE CONTROL:

- **SPEAKER**, *Making Dialysis Safer for Patients Coalition National Launch, "Patient Concerns Regarding Dialysis Safety and Quality," Atlanta, Georgia, September, 2016.*

CENTERS FOR MEDICARE AND MEDICAID ASSISTANCE:

- **INVITED SPEAKER**, *CMS Quality Conference, "Strategies for Improving and Retaining Employment Opportunities for People with Kidney Disease, Baltimore, Maryland, January, 2019.*

- **SPEAKER**, *CMS Person and Family Engagement and Kidney Health Affinity Group*, discussion on how HHS and CMS can better incorporate patient experience to improve the Federal policy and the healthcare system, Baltimore, Maryland, April, 2018.
- **SPEAKER**, *CMS Quality Conference*, “Keeping Pre-Dialysis Kidney Patients Employed & in the Workforce – a Review of the KidneyWorks National Collaborative,” Baltimore, Maryland, January, 2018.
- **MEMBER**, *Technical Evaluation Panel (TEP), End Stage Renal Disease (ESRD) Patient Reported Outcomes (PRO)*, administered under CMS contract with the University of Michigan Kidney Epidemiology and Cost Center (UM-KECC), March 2017 to present.
- **CO-CHAIR**, *Technical Evaluation Panel (TEP), ESRD Dialysis Facility Compare (DFC) Star Ratings, Quality Measure Development, Maintenance, and Support Project*, administered under CMS contract with the University of Michigan Kidney Epidemiology and Cost Center (UM-KECC), January 2017 to present.
- **SPEAKER**, *CMS Quality Conference*, “Dialysis Facility Compare (DFC), End Stage Renal Disease (ESRD) Quality Incentive Program (QIP): Two Medicare Programs for Evaluating Performance and Improving Patient Care - a Patient Perspective,” Baltimore, Maryland, December, 2016.
- **PANELIST**, *CMS Quality Conference*, “Patient Experiences with Dialysis, How Patients Define Quality of Care,” Baltimore, Maryland, December, 2016.
- **PARTICIPANT**, *CMS Rollout of Dialysis Facility Compare Star Rating, national rollout conference call*, October, 2015.
- **CO-CHAIR**, *Technical Evaluation Panel (TEP) Patient/Consumer Advocate Workgroup, ESRD Dialysis Facility Compare (DFC) Star Ratings*, administered under CMS contract with the University of Michigan Kidney Epidemiology and Cost Center (UM-KECC), May-August, 2015.
- **SPEAKER**, *Centers for Medicare and Medicaid Innovation (CMMI), Stakeholder Meeting with CMS Administrator Marilyn Tavenner, ESRD Dialysis Facility Compare (DFC) Star Ratings*, September, 2014.
- **EXPERT PUBLIC TESTIMONY**, *Centers for Medicare and Medicaid Services, Medicare Evidence Development & Coverage Advisory Committee (MEDCAC)*, January, 2011.
- **EXPERT PUBLIC TESTIMONY**, *Centers for Medicare & Medicaid Services End State Renal Disease bundle payment system*, October, 2009.

CENTERS FOR MEDICARE AND MEDICAID INNOVATION:

- **PARTICIPANT**, *stakeholder discussion on insights into the experience of beneficiaries in the CEC Model and applicability of the KDQoL survey*, teleconference, February, 2108.
- **EXPERT PANEL MEMBER**, *Centers for Medicare and Medicaid Innovation (CMMI), ESRD Care Initiative, (ESCO), (SDO – Small Dialysis Organizations) Healthcare Management Solutions, LLC (HMS)*, October, 2014.
- **EXPERT PANEL MEMBER**, *Centers for Medicare and Medicaid Innovation (CMMI), ESRD Care Initiative, (ESCO), (LDO – Large Dialysis Organizations), Healthcare Management Solutions, LLC (HMS)*, July 2014.

- **PARTICIPANT**, *stakeholder meeting with Dr. Patrick Conway, regarding ESRD Seamless Care Organization (ESCO) program, September, 2013.*

CONGRESSIONAL BUDGET OFFICE:

- **EXPERT STAKEHOLDER**, *discussion with Chief, Health Systems and Medicare Cost Estimates Unit, regarding kidney transplant patient access to immunosuppressive drugs after 36 months - and the estimated positive cost-savings to kidney transplant patients under the Immunosuppressive Drug Coverage Legislation (HR 1428/S 323), November, 2014.*

HEALTH RESOURCES AND SERVICES ADMINISTRATION:

- **EXPERT PARTICIPANT**, *HRSA patient advocacy organization stakeholder meeting on living donor organ donation education programs, August, 2015.*
- **EXPERT PARTICIPANT**, *HRSA patient advocacy organization stakeholder meeting on living donor organ donation education programs, January, 2015.*

FOOD AND DRUG ADMINISTRATION:

- **EXPERT PUBLIC TESTIMONY**, *Food and Drug Administration, Cardiovascular and Renal Drugs Advisory Committee, October, 2010.*

GOVERNMENT ACCOUNTABILITY OFFICE:

- **STAKEHOLDER**, *interview for GAO report, “National Institutes of Health: Kidney Disease Research Funding and Priority Setting.” The report was produced in accordance with a request to the GAO to study potential comparative disparities in disease research funding between kidney and other diseases from The Honorable Barbara Comstock, Chairwoman Subcommittee on Research and Technology Committee on Science, Space, and Technology, U.S. House of Representatives, May, 2016.*
- **STAKEHOLDER**, *interview for GAO report, “End Stage Renal Disease: CMS Should Assess Adequacy of Payment When Certain Oral Drugs Are Included and Ensure Availability of Quality Monitoring Data.” The GAO report was produced in accordance with a mandate in the Patient Protection and Affordable Care Act (ACA), March 28, 2011.*

NATIONAL INSTITUTES OF HEALTH/NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES:

- **STEERING COMMITTEE MEMBER**, *Kidney Precision Medicine Project (KPMP) Launch, August 2017 through January 2018.*
- **SPEAKER**, *Kidney Precision Medicine Project Workshop, “Patient Perspectives on Research Biopsy,” May, 2016.*

SELECT KIDNEY NGO ENGAGEMENT & ADVOCACY ROLES

ALLIANCE FOR HOME DIALYSIS

- **PARTICIPANT**, *Federal Policy Workshop on Access and Innovation in Home Dialysis, July 2015.*

AMERICAN NEPHROLOGY NURSES ASSOCIATION

- **PARTICIPANT AND AAKP CO-SPONSOR**, *Congressional Kidney Caucus Briefing, Washington, D.C., March 20, 2013.*

AMERICAN SOCIETY FOR ARTIFICIAL INTERNAL ORGANS

- **PARTICIPANT**, *63rd Annual Conference, Chicago, Illinois, June 2017.*

AMERICAN SOCIETY OF NEPHROLOGY

- **FACULTY AND EXPERT PARTICIPANT**, *ASN Kidney Week, November, 2018.*
- **SPEAKER**, *Kidney Community Advocacy Day, September, 2018.*
- **SPEAKER**, *roundtable with Secretary Alex Azar, May 2018.*
- **SPEAKER**, *ASN/AAKP Kidney Health Advocacy Day, March, 2018.*
- **FACULTY AND EXPERT PARTICIPANT**, *ASN Kidney Week, November, 2017.*
- **SPEAKER**, *Kidney Community Advocacy Day, Washington, D.C., September, 2017.*
- **CONTRIBUTING AUTHOR**, *“Advancing Technologies to Facilitate Remote Monitoring of Patient Self-Care in Renal Replacement Therapy: Perspectives from the Kidney Health Initiative” July, 2017.*
- **SPEAKER**, *ASN/AAKP Kidney Health Advocacy Day, March, 2017.*
- **FACULTY AND EXPERT PARTICIPANT**, *ASN Kidney Week, November, 2016.*
- **SPEAKER**, *Kidney Health Advocacy Day, “The Role of the Patient Voice in Policy Development,” April, 2016.*
- **FACULTY**, *ASN Kidney Week 2015, “Curing Kidney Disease: At the Crossroads of Biology, Infrastructure, Patients, and Government,” November 4, 2015.*
- **SPEAKER**, *Kidney Community Advocacy Day, September, 2015.*
- **SPEAKER**, *Speaker, Kidney Community Advocacy Summit, November, 2014.*
- **FACULTY**, *Kidney Week 2014, “Clinical Trial End Points: Jumping the Barriers,” November, 2014.*
- **EXPERT PARTICIPANT**, *Capitol Hill Kidney Health Advocacy Day, May, 2014.*
- **EXPERT PARTICIPANT**, *Capitol Hill Kidney Health Advocacy Day, April, 2013.*

AMERICAN SOCIETY OF TRANSPLANTATION

- **SPEAKER AND PARTICIPANT**, *Inaugural Transplant Patient Congress, October, 2017*
- **SPEAKER**, *AST Patient Stakeholder Meeting, February, 2016.*
- **SPEAKER**, *AST Inaugural Patient Stakeholder Meeting, June, 2015.*
- **PARTICIPANT**, *Congressional Briefing, Immunosuppressive Drugs, August, 2009.*

AMERICAN SOCIETY OF TRANSPLANT SURGEONS

- **PARTICIPANT**, *Congressional Briefing, Patient Views on Dialysis Patients Demonstration Act, September, 2018.*
- **PARTICIPANT**, *Congressional Briefing, Transplant Demonstration Model Legislation, September, 2017.*
- **PARTICIPANT**, *Congressional Briefing, Integrative Care Model Legislation, August, 2016.*
- **PARTICIPANT**, *Kidney Transplant Roundtable, Washington D.C., 2009 - present.*

CARDIO RENAL SOCIETY OF AMERICA AND NATIONAL KIDNEY FOUNDATION OF ARIZONA

- **FACULTY AND SPEAKER**, *18th Annual Southwest Nephrology Conference and 5th Annual Cardio Renal Society of America (CRSA) Cardio Renal Metabolic Conference, "Patient Centric Innovation,"* October, 2017.

CLINICAL TRIALS TRANSFORMATION INITIATIVE

- **TEAM MEMBER**, *Legal and Regulatory Project*, June 2015 - October 2018.
- **MODERATOR**, *Legal & Regulatory Issues Affecting the Adoption of Mobile Clinical Trials - A Multi-Stakeholder Expert Meeting*, July, 2017.
- **PARTICIPANT**, *Stakeholder Planning Meeting*, December, 2016.

DUKE UNIVERSITY MARGOLIS CENTER FOR HEALTH POLICY

- **PARTICIPANT**, *Expert Workshop, "Incorporating Real-World Evidence in Regulatory Decision-Making: A Pragmatic Approach to Randomization in the Clinical Setting,"* January, 2016.

FRIENDS OF THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

- **PARTICIPANT**, *Congressional Sponsors Event with Dr. Griffin Rodgers*, June, 2015.

GLOBAL BIOETHICS INSTITUTE, UNITED NATIONS HEADQUARTERS

- **SPEAKER**, *Conference on Advancing the Policy Debate on End of Life Care*, speech entitled *"Patient Engagement & Advocacy: The Disproportionate Force for Science, Policy and Ethics,"* New York City, New York, April, 2018.

HEALTH CARE READY

- **EXPERT PARTICIPANT**, *Diseases and Disasters Roundtable Discussion*, March, 2017.

HEALTH IS PRIMARY

- **PARTICIPANT**, *"Partners in Practice: Working Together to Deliver on the Triple Aim,"* May, 2015.

KIDNEY HEALTH INITIATIVE

- **CO-CHAIR**, *Seventh Annual Stakeholder Meeting*, April, 2019
- **CO-CHAIR AND SPEAKER**, *Sixth Annual Stakeholder Meeting*, June, 2018
- **PARTICIPANT**, *"Developing a Roadmap for Innovative Alternatives to Renal Replacements Therapy,"* American Society for Artificial Implantable Organs June, 2017.
- **PANEL SPEAKER**, *Fifth Annual Stakeholder Meeting*, June, 2017.
- **PARTICIPANT**, *Fourth Annual Stakeholder Meeting*, June, 2016.
- **SPEAKER AND TEAM LEADER**, *Kidney Community Advocacy Day*, September, 2015.
- **SPEAKER**, *"Understanding Patient Preference: Stimulating Medical Device Development,"* KHI workshop, August, 2015.

- **PARTICIPANT**, *Third Annual Stakeholder Meeting, June, 2015.*
- **ADVISORY PARTICIPANT**, *KHI White Paper, “Advancing Technologies to Facilitate Remote Management of Patient Self-care in Renal Replacement Therapy,” May 2015.*
- **PANEL SPEAKER**, *Second Annual Stakeholder Meeting, June, 2014.*
- **FOUNDING ORGANIZATIONAL MEMBER**, *Inaugural Stakeholder Meeting, June, 2013.*

LIFENET HEALTH FOUNDATION

- **SURROGATE SPEAKER**, *multiple venues, 1997-2001.*
- **SPEAKER TRAINING**, *October, 1997.*

MID-ATLANTIC RENAL COALITION

- **BOARD MEMBER**, *(CMS ESRD Network 5 contracted agency), March 2013 through present.*
- **PARTICIPANT**, *Forum of ESRD Networks Quality Conference, 2015.*
- **MEMBER**, *Patient & Family Engagement Work Group, 2014 through 2016.*
- **SPEAKER**, *Kidney Health Outcomes, Arlington, VA, 2010.*
- **SPEAKER**, *“Perspectives on Dialysis Quality and Transplantation,” Denver, Colorado, June, 2009.*

MILKEN INSTITUTE, CENTER FOR STRATEGIC PHILANTHROPY

- **GUEST PARTICIPANT**, *Milken Institute, ESRD Call to Action Retreat, “Improving Dialysis Outcomes – The Path Forward,” New York City, New York, October, 2016.*

NATIONAL ASSOCIATION FOR THE ADVANCEMENT OF COLORED PEOPLE

- **SPEAKER**, *“Pop-Up Kidney Care Forum,” NAACP National Meeting, June, 2017.*

NATIONAL COMMITTEE FOR QUALITY ASSURANCE

- **MEMBER**, *Technical Evaluation Panel (TEP), NCQA/IMPAQ International, proposed performance measure for the Comprehensive End-Stage Renal Disease (ESRD) Care Model using the Kidney Disease Quality of Life (KDQOL) survey, December 2016 through present.*

NATIONAL COUNCIL ON PATIENT INFORMATION AND EDUCATION

- **EXPERT STAKEHOLDER**, *3rd Seeking Solutions Stakeholders Forum on Advancing Our Understanding of the Safe Use of Acetaminophen, March, 2015.*

NATIONAL KIDNEY FOUNDATION

- **SPEAKER**, *National Kidney Foundation for the 4th Annual Kidney Patient Summit, March 6-7, 2017.*
- **SPEAKER**, *NKF 3RD Annual Kidney Patient Summit, March, 2016.*
- **PARTICIPANT**, *Briefing on the State of Chronic Kidney Disease, July, 2015.*
- **PARTICIPANT**, *NKF 2nd Annual Kidney Patient Summit, June, 2015.*
- **MEMBER**, *NKF Transaction Council, 1997 through 2000.*

NATIONAL OPINION RESEARCH CENTER/KETCHUM COMMUNICATIONS

- **COORDINATOR**, *Kidney Patient Roundtable Meeting, Washington, D.C. May, 2017.*

NATIONAL RENAL ADMINISTRATORS ASSOCIATION

- **SPEAKER**, *“Effective Congressional Advocacy,” NRAA Hill Day, May, 2015.*

PATIENT ACCESS TO PAIN RELIEF COALITION

- **PRESENTER**, *PAPR Invitational Stakeholder Meeting, May, 2018.*
- **PARTICIPANT**, *Congressional staff briefings, October, 2017.*
- **PRESENTER**, *FDA, Center for Drug Evaluation and Research, July, 2016.*
- **SPEAKER**, *Pain Relief Policy Congressional Briefing, United States Capitol, June, 2016.*
- **PARTICIPANT**, *Congressional staff briefings, July, 2016.*
- **PRESENTER**, *FDA, Center for Drug Evaluation and Research, January, 2016.*
- **PRESENTER**, *FDA, Center for Drug Evaluation and Research, September, 2015.*
- **PRESENTER**, *PAPR Invitational Stakeholder Meeting, June, 2015.*

POLYCYSTIC KIDNEY DISEASE FOUNDATION

- **NATIONAL BOARD MEMBER**, 2013-2016.
 - Member, *Public Policy Committee, 2013-2016.*
 - Member, *Executive Director Search Committee, 2014.*
- **CO-HOST**, *with former U.S. Senator Robert Bennett (UT), Understanding Kidney Advocacy, National Webinar, 2014.*
- **CO-PRESENTER**, *with former U.S. Senator Robert Bennett (UT), PKDF National Patient Meeting, “Effective Patient Advocacy Strategies,” 2014.*
- **PARTICIPANT**, *United on the Hill Congressional visits, 2013.*
- **TRAINING LECTURER**, *United on the Hill, “The Role of Effective Patient Advocacy in the Public Policy Process” and “The National Kidney Community – A cursory Glance at Common Legislative Priorities,” 2013.*

RENAL PHYSICIANS ASSOCIATION

- **SPEAKER**, *“Being an Effective Leader in Advocacy,” RPA Annual Conference, Miami, Florida, March, 2018*
- **SPEAKER**, *Nephrology Coverage Advocacy Program (NCAP) Meeting, “Charitable Assistance & 3rd party Payment,” June 2017.*
- **EXPERT PARTICIPANT**, *Hill Day Visit, June 2016.*
- **EXPERT PARTICIPANT**, *Hill Day Visit, May, 2015.*
- **SPEAKER**, *Medal of Excellence Awards Event, Annual Meeting, March, 2015.*
- **EXPERT PARTICIPANT**, *Hill Day Visit, May, 2014.*
- **EXPERT PARTICIPANT**, *Hill Day Visit, June, 2013.*

ROGOSIN INSTITUTE

- **SPEAKER**, *Annual “Circle of Friends” Reception, “Patient Engagement and Improved Quality Outcomes,” March, 2017.*

- **SPEAKER**, Rogosin Institute Symposium “Integrative Kidney Care: Is it Achievable?” cosponsored by New York-Presbyterian Regional Hospital Network and New York-Presbyterian/Queens at The Rockefeller University, October, 2016.

UNITED NETWORK FOR ORGAN SHARING

- **SURROGATE TRANSPLANT SPEAKER**: Hillel (Virginia Beach, VA); Catholic Youth Organization (CYO, Norfolk, VA); Rotary Club International (Smithfield, VA); Lions Club (Virginia Beach, VA); Boy Scouts of America (Newport News, VA); Certified Registered Nurses Continuing Education Program (Norfolk, VA); Virginia Beach Festival, (Virginia Beach, VA); Norfolk and Tidewater Virginia, 1996 – 2001.