CHRISTIANA CARE VALUE INSTITUTE

2017 FALL SYMPOSIUM

Engaging Stakeholders for a Patient-Centered Agenda for Chronic Kidney Disease in Delaware

Partners in Research

FRIDAY, SEPTEMBER 15 | 8 A.M. – 1:30 P.M.
John H. Ammon Medical Education Center, Christiana Hospital campus
AGENDA

REGISTRATION AND BREAKFAST | 7:30 AM

Welcome and Updates | 8:00 AM
Claudine T. Jurkovitz, MD, MPH, Senior Physician Scientist
Value Institute, Christiana Care Health System

Addressing Challenges of Transition in Pediatric CKD Patients | 8:10 AM
Joshua J. Zaritsky, MD, PhD, Chief of Pediatric Nephrology
Nemours/Alfred I. duPont Hospital for Children

The Patient Experience | 9:05 AM
Shawn R. Smith, MBA, Vice President of Patient Experience
Christiana Care Health System

BREAK | 9:25 AM

One Caregiver’s Journey and Lessons to Share | 9:30 AM
Margaret R. Poppiti, RN, BSN, MS, Patient Advocate

Understanding the Patient Experience of Kidney Disease | 9:40 AM
Amar D. Bansal, MD, Assistant Professor of Medicine
University of Pittsburgh Medical Center

BREAK | 10:35 AM

Exercise for Rehabilitation in Chronic Kidney Disease (Renal Rehab) | 10:45 AM
David G. Edwards, PhD, Professor
Department of Kinesiology and Applied Physiology, University of Delaware

Living with Polycystic Kidney Disease | 11:40 AM
Vincent R. Skrezyna, Sr., Patient

NETWORKING LUNCH | 11:55 AM

PREPARE NOW: Putting Patients at the Center of Kidney Care | 12:25 PM
Jamie A. Green, MD, MS, Nephrologist/Clinical Investigator
Geisinger Health System

Conclusion | 1:20 PM
Claudine T. Jurkovitz, MD, MPH, Senior Physician Scientist
Value Institute, Christiana Care Health System
Accreditation Statement

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the Medical Society of Delaware and the Christiana Care Health System.

The Medical Society of Delaware designates this live continuing medical education activity for a maximum of 3.75 AMA PRA Category 1 Credit™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

It is the policy of the Medical Society of Delaware to comply with the ACCME Standards for Commercial Support of Continuing Medical Education. In keeping with these standards, all faculty participating in continuing medical education activities jointly provided by the Medical Society of Delaware are expected to disclose to the activity audience any real or apparent conflicts of interest related to the content of their presentation. Joint providership of CME by the Medical Society of Delaware in no way implies endorsement or recommendation of any product or services.

This activity is not supported by commercial funding.
INVITED SPEAKERS (IN ORDER OF APPEARANCE)

Joshua J. Zaritsky, MD, PhD is Chief of the Division of Nephrology at the Nemours/Alfred I. duPont Hospital for Children. He is a graduate of Stanford School of Medicine. Dr Zaritsky completed his residency in pediatrics at Denver Children’s Hospital and completed a fellowship in pediatric nephrology at Mattel Children’s Hospital at UCLA. He is board certified in both Pediatrics and Pediatric Nephrology. He has lectured and published extensively in the fields of chronic kidney disease, iron metabolism and metabolic bone disease. He is active in several national and international pediatric nephrology research collaboratives. His special interests include acid-base and electrolyte abnormalities, acute kidney injury, dialysis, and renal transplantation.

Shawn R. Smith is the Vice President of Patient Experience at Christiana Care Health System. Shawn has over fifteen years in customer experience leadership including eight years in the hospitality industry working for world’s largest branded-casino entertainment company Caesar’s Entertainment.

At Christiana Care, he leads the organization in the development and execution of strategies to impact the patient’s experience across nine service lines that ultimately drives outcomes to the highest levels. These strategies include enabling a culture of patient-family centered care; deploying innovative tools and training solutions to create breakthroughs in behavior change; oversight of regulatory experience surveying & complaint management; and, advancement of our culture – The Christiana Care Way. The patient experience division includes visitor & volunteer services, patient relations, and patient experience program management resources.

Shawn received a bachelor’s degree in hospitality management from Widener University, an MBA from the Villanova School of Business and a certificate in Federal mediation and conciliation services. He also serves on the Advisory Panel of Press Ganey’s Academic Special Interest Group, Advisory Board member of the Beryl Institute and is a Board Member for the Better Business Bureau of Delaware.
Margaret R. Poppiti, RN, BSN, MS, was a wife and mother of four whose husband and three sons all inherited Polycystic Kidney Disease (PKD). Peggy’s determination to care for her husband and her concerns for her sons led her to learn everything she could about the disease following her husband’s diagnosis. She became a Home Hemodialysis partner for her husband when he advanced to End Stage Renal Disease (ESRD) and also attended the University of Delaware, graduating with a BSN in 1983 and then working as a Registered Nurse at the VA Hospital, assisting with opening the VA Hospital’s Acute/Chronic Hemodialysis Unit. Peggy continued her education and graduated from St. Joseph’s University in 1993 with a Masters in Health Education and taught two semesters at Delaware Technical College, training Hemodialysis technicians. She also authored a chapter on the renal system in the textbook “Fluid & Electrolyte.” Peggy retired from the VA in 2007 and began working per diem for Fresenius Medical Care at the St. Francis Hospital Acute Dialysis Unit, where she continues working today. Peggy is a Governor-appointed member of the Delaware State Chronic Renal Disease Advisory Board.

Peggy’s husband received a kidney transplant in 1984, but following a stroke in 1990, he lost the use of his dominant left side. In 1998, his transplant failed and two months later his access clotted. He passed away in 1998 after making the decision to stop dialysis. In 2007, Peggy’s eldest son started renal replacement therapy. He later received a transplant. Her second son started chronic Hemodialysis 3 years ago, and her third son has not (yet) reached ESRD. He is actively monitoring his blood pressure.

Peggy is determined to continue to work and maintain involvement with the renal community so that she can serve as a resource and support for her sons as well as other patients in the PKD community. A housewife turned advocate, Peggy believes in living in hope for a cure!

Amar D. Bansal, MD, completed medical school at NYU and postgraduate training in internal medicine and nephrology at the University of Pennsylvania. He had a long interest in laboratory science and was involved in bench research until 2015. His interest in serious illness, palliative care, and end of life care led him to pursue a palliative care fellowship. He is now an Assistant Professor of
Medicine at University of Pittsburgh where he is active on both the nephrology and palliative care services. He has clinical and research interests in renal supportive care and onconephrology, with dedicated clinics for both.

**David G. Edwards, PhD,** is a Professor in the Department of Kinesiology and Applied Physiology at the University of Delaware in Newark, DE. He received his BS from the University of Delaware, MS from Wake Forest University, and PhD from the University of Florida. His research is focused on exercise and cardiovascular function in chronic kidney disease and he has established a Renal Rehab program at UD. His other area of research focuses on the vascular effects of dietary sodium. His research has been funded by the National Institutes of Health and the American Heart Association. He also leads the NIH funded Center of Biomedical Research Excellence (COBRE) in Cardiovascular Health at UD. The goal of this COBRE is to develop a sustainable center that catalyzes cardiovascular research and strengthens the infrastructure for cardiovascular research at UD. Additionally, he serves as the Cardiovascular Research Theme Leader for Delaware INBRE.

**Vincent R. Skrezyna, Sr.**, was on dialysis for seven years until his kidney transplant at Christiana Care. Polycystic Kidney Disease (PKD) can be traced back four generations in Vince’s family. His maternal grandfather and his grandfather’s sister had PKD and Vince’s mother was diagnosed with PKD in 1981. Shortly after his mother started dialysis, Vince found out that he carried the gene for PKD as well. Vince and his wife Carmen have five children; his three daughters have all tested positive for the PKD gene.

Vince first experienced symptoms of the disease in 2003, and shortly after, at 58 years old, Vince started dialysis – the same as his mother when she went on dialysis 30 years before. After seven years on dialysis, Vince received a kidney transplant in October 2010.

Vince hopes that by speaking about his experience, he can bring hope to patients and families diagnosed with PKD and demonstrate that anyone can learn to move on with their life. He hopes that all PKD patients hold onto hope, because without hope there is no future. Vince’s battle is
ongoing, and until a cure is discovered for PKD, all people affected by this disease need to keep fighting!

**Jamie A. Green, MD,** received her undergraduate degree from Duquesne University and her medical degree from Temple University School of Medicine. She completed her Internal Medicine Residency at the Massachusetts General Hospital and her Nephrology Fellowship at the University of Pittsburgh where she also obtained her Master of Science in Medical Education. She came to Geisinger in 2012 and is currently an Associate Physician in the Nephrology Department and Assistant Professor of Clinical Research in the Kidney Health Research Institute where her work focuses on patient engagement, health literacy, and shared decision making. Jamie is the co-Principal Investigator of a PCORI funded project PREPARE NOW to examine the impact of patient-centered kidney transitions care on patient empowerment and well-being. She is Core Faculty for the Nephrology Fellowship, the Internal Medicine Residency Program, and the Geisinger Institute for Advanced Applications. She also serves on the Patient Engagement/Learning Health Care Work Group and the Health Literacy Committee at Geisinger.
PARTNERS IN RESEARCH LEADERSHIP

Claudine Jurkovitz, MD, MPH, is the Principal Investigator for Partners in Research project. She is Senior Physician Scientist in the Value Institute at Christiana Care and Director of the Biostatistics, Epidemiology and Research Design core of the Delaware Center and Translational Research ACCEL program. In these roles, she helps physicians, residents and young investigators develop their research projects and analytical plans and works closely with the Value Institute data management team. She is also an active member of the steering committee of the INBRE Bioinformatics Network of Delaware (BiND).

As a Nephrologist Epidemiologist, Claudine has actively developed her own research interests, mostly in the field of chronic kidney disease (CKD) and health services research. She was recently awarded a Big Data Pilot grant through the ACCEL program, "Linking Data for Kidney Care", to build a CKD registry in the State of Delaware by linking electronic health records to predict hospitalizations in patients with CKD and examine the transition from pediatric to adult care in young adults with CKD.

From December 2005 to July 2012, Claudine was the Director of Operations of the Christiana Care Center for Outcomes Research (CCOR) and supervised the day-to-day management of the center and worked closely with Dr. William Weintraub (CCOR Director) and the Director of Biostatistics to establish research priorities. Prior to working at Christiana Care, she was Assistant Professor of Medicine at Emory University in Atlanta. While pursuing her research interest in the prevention of progression of kidney disease, she also became an active member of the Institutional Review Board (IRB) and was later nominated vice chair of the Emory University IRB.

Nancy Scott, MS, is a retired nurse and an ordained minister. She is currently pursuing a doctorate in Industrial Organizational Psychology. Nancy was on dialysis for seven years and received a kidney transplant in 2011. While Nancy was on dialysis, she started a support group in her unit and became a member of Dialysis Patient Citizens. Dialysis Patient Citizens, located in Washington, DC, is a non-profit organization dedicated and committed to improving the quality of life of renal patients through advocacy and education. After two years, Nancy became the President and continues to advocate on Capitol Hill and regularly speaks at
symposiums and conferences. After Nancy’s transplant, she became the President of a sister organization, Dialysis Patient Citizens Education Center, and continues to educate renal, dialysis and transplant patients. Nancy is also currently Chair of the Board of Directors at Henrietta Johnson Medical Center in Wilmington, DE.

Nancy often begins her speeches with: “Dialysis does not mean the end of your life.” She continues to encourage and empower patients by telling them her story and accomplishments after dialysis. She is also committed to educating everyone about the prevention of renal disease. Knowledge is empowerment!

**Joanne Smith, RN,** is the Fresenius Kidney Care Patient Care Advocate for New Castle, Kent, and Sussex counties in Delaware and Salisbury and Princess Anne in Maryland. Previously, she was Home Therapies Manager at Fresenius Medical Care in Newark, DE, managing one of the largest home dialysis programs in the country. That clinic is now certified as a progressive transitional dialysis facility with a stand-alone home clinic. Joanne was also Education Manager for Dialysis Patient Citizens in Washington, DC, an advocacy organization for patients with chronic kidney disease. She has been involved in education efforts for patients diagnosed with kidney disease of all stages, including end stage renal disease (ESRD), specifically discussing available treatment options for ESRD.

Joanne has written a number of articles and provided editorial content in Dialysis Patients Citizens’ monthly e-newsletters. She worked with Kidney Care Partners in Washington, DC where they are helping CMS create and revise critical quality indicators and weighing capabilities for Medicare reimbursement for treatment, and worked with Home Alliance, also in Washington, DC, where she was working with Medicare contractors as a stakeholder in establishing Medicare beneficiary access to more frequent hemodialysis. Joanne is a board member of Henrietta Johnson Health Center and Health Policy Representative as well as a chapter officer for the Delaware American Nephrology Nurses’ Association (ANNA), advocating for CKD and ESRD patients in Washington, DC, and meeting and educating Delaware delegates on kidney disease and current legislation. She has been a Delaware Medical Reserve Corp volunteer for 5 years providing assistance to the state of Delaware in emergency situations.

In recognition of her outstanding leadership, innovation and caring, Joanne was named the 2016 Ernestine Lowrie Award winner in March 2016 at the Clinical Managers’ Conference in Indianapolis. The Lowrie Award, given annually to a Fresenius Kidney Care employee, recognizes the employee that best exemplifies the core values and behaviors of Fresenius
Medical Care as well as their mission to provide superior care that improves the quality of life of every patient every day. Joanne donated a kidney to a home dialysis patient in August 2015.

Timothy Gibbs, MPH, a Delaware native, has worked in the nonprofit sector for most of his career. A graduate of Earlham College with major coursework in biology and psychology, Tim’s Quaker background and values have steered much of his focus on community and social service concerns. He was in the first graduating class from the University of Delaware in nonprofit management. Mid-career he completed his master’s degree in public health from Arcadia University.

As a nonprofit executive with a career spanning over 30 years he has focused on two key areas: public health and the effective and appropriate use of technology to aid in the process of human services delivery. Across this arc of time we have seen the rise of computers, the internet, and mobile devices. We have also witnessed alarming trends in public health including the emergence of new infectious diseases, trends toward wide spread Metabolic Syndrome (CVD, Diabetes, Obesity), and an aging population presenting its own unique challenges. Coupled with this we have seen a transformation in how care is delivered – moving from payment for services to payment for quality coupled with a renewed focus on the importance of prevention.

Tim serves on the boards of many local and national organizations including the American Public Health Association and is an active member of the Wilmington Rotary.

Heather Bittner Fagan, MD, MPH, FAAFP, is a practicing family physician and researcher. Dr. Fagan is an Associate Professor at Thomas Jefferson University in Philadelphia, the Associate Vice Chair for Research in Family & Community Medicine at Christiana Care Health System, and is the Director of the Community Engagement and Outreach core of the Delaware Clinical and Translational Research ACCEL program.

Dr. Fagan has made regional and national contributions to research on cancer screening and shared decision making in primary care and underserved populations. She has also made regional and national contributions on methods of community engagement, specifically engaging physicians and their primary care practices and building community-academic teams. Dr. Fagan received the American Cancer Society’s Cancer Control Career Development Award, which recognizes and develops national leaders in cancer control and prevention, and has received research funding from the National
Cancer Institute. Dr. Fagan serves on the Institutional Review Board (IRB) for Christiana Care and the University of Delaware. She is a fellow of the American Academy of Family Physicians and a member of professional organizations including the Society of Teachers of Family Medicine, North American Primary Care Research Group, and the Medical Society of Delaware. She also serves as a board member of the Delaware Academy of Family Physicians and an invited member of the Delaware Health Care Consortium’s Early Detection and Prevention Committee.

**Shay Scott, MA,** is the Director of Operations at Henrietta Johnson Medical Center (HJMC) in Wilmington, DE. She is responsible for the management of staff in developing and implementing Henrietta Johnson Medical Center’s mission and strategic plan. She works in conjunction with the CEO to develop practice transformational strategies and adopt process improvement tools and methods. She also assists the clinical and administrative teams with program development and implementation and oversees community outreach programs with organizations in HJMC’s service area.

Previously, Shay served as HJMC’s Fund Development Director. In this role, she was responsible for researching and preparing grant proposals and providing ongoing grant oversight. She also developed year-end-appeal and underwriting requests, and managed all fundraising programs for the health center. Prior to joining HJMC, Shay served as the Director of Veteran and Housing First Services for Connections CSP, Inc., a private non-profit social services agency in Wilmington, DE where she provided oversight for Supportive Services For Veteran Families funding and sub-grantees and was responsible for planning, implementing and supervising program activities that provided outreach, case management, and financial assistance for Veterans experiencing homelessness or in imminent risk of becoming homeless. In 2007, Shay participated in Leadership Delaware, an initiative of the Delaware Association of Nonprofit Agencies (DANA) designed to train individuals in becoming nonprofit board members. She takes part in ongoing conferences and workshops regarding cultural competency, trauma informed care, and community redevelopment in addition to health center quality and operational efficiency conferences.
PARTNERS IN RESEARCH STAKEHOLDER TEAM

Sarahfaye Dolman, MPH, MTA, is a research associate/data analyst at the Christiana Care Value Institute. She has considerable experience managing research projects, data, and personnel and has been involved with Partners in Care and Research since its inception. Prior to working at the Value Institute, Sarahfaye worked at the University of Delaware where she coordinated a longitudinal research intervention in the Human Emotions Lab in the Department of Psychology. Her experience includes coordinating efforts between multiple institutions, managing research personnel, maintaining participant databases, completing quality assurance checks on data, and reporting on data quality. She also has experience in data coding and developing research tools, coding systems, and intervention materials.

Sarahfaye is a certified Microsoft Technology Associate with interests in the management of data in the context of research and the application or translation of research findings to public health and healthcare. She is broadly interested in the design, use, and evaluation of systems for the collection, management, analysis, and reporting of information for research purposes.

William “Bill” Murray was a self-employed plumber for his company, Shamrock Plumbing, until Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD) forced him to shutter the company and take disability.

Bill was biopsy diagnosed with IgA Nephropathy in 1996, when his nephrologist told him that he would require dialysis to live. He followed the doctor’s orders, implementing lifestyle changes and dietary restrictions (along with a mind boggling amount of medicine that was constantly modified) for the next 17 years until his kidney function dropped into the danger zone and he went into end stage renal failure. But he spent those years researching his disease and all of the available treatment options. He discovered that home dialysis was the most effective and had the best results. He started on peritoneal dialysis (PD), but weight gain and complications from diabetes caused him to switch to home hemodialysis (HHD) after 10 months. He has continued this mode of treatment very successfully since. Bill is constantly promoting the advantages of home hemodialysis. The freedom from strict in-center scheduling hours, the flexibility of dialysis days, improved physical strength following dialysis, and the closer approximation to natural kidney function are benefits of HHD that Bill continues to share.
Bill’s personal experience has ignited his passion for early detection, education, organ availability, and donor support. He has become an active fundraiser and participates in all kidney-related Walks in the Delaware/Philadelphia region. He has also become an active advocate both locally and nationally for National Kidney Foundation (NKF), Nephcure Kidney International (NKI), and Gift of Life Donor Foundation and fills roles as diverse as patient representative, patient action committee member, and a subject matter expert across these organizations. Bill also serves as a peer mentor for both NKF and NKI and has been recruited by NxStage to become one of their national advocates for home hemodialysis treatment options.

Bill has received many honors for his advocacy work. He was recognized by Gift of Life in 2014 as their outstanding first year volunteer and he was recently recognized by NKF Delaware Valley as their outstanding advocate on World Kidney Day 2017.

**Steven Scott** was diagnosed with Polycystic Kidney Disease (PKD) when he was 15. In 2003 he went into kidney failure and began hemodialysis. In 2007, Steve received a kidney transplant and was diagnosed with diabetes at the same time. He had his native kidneys in 2008. An infection in 2015 caused him to reenter kidney failure and he resumed in-home hemodialysis. Steve tried peritoneal dialysis for a year and is currently performing in-home hemodialysis with his wife Jeannie.

Steve has been married to his lovely wife of 33 years, Jeannie Scott. He has two sons, Michael and Jeff, and loves spending time with his granddaughter. Steve is a huge fan of sports and is a regular attendee at UD football games. Steve is currently on disability but looking for a part-time job. He fills his time by spending time with family and educating other CKD patients about the disease.

**Katherine Smith, MD, MPH,** has a background in both medicine and public health and has led research projects on foreign and domestic immunization practices, the role of women and sexism in American society, and the use of advance directives in Delaware. The results of her research have led to new practices for heat-stable vaccines and high-heat cold chain breaks in New South Wales, Australia, and the normalization of end-of-life conversations.

Dr. Smith has worked to improve the health of residents of Aruba, as well as people in Atlanta and Chicago, and has
fought for the health and well-being of children throughout her career. Her dual degree and dual citizenship – with both the United States and Australia – allow her a unique perspective on medicine, public health, and how these concentrations interact on an international stage.

As a program manager for the Delaware Academy of Medicine and the Delaware Public Health Association, Dr. Smith uses her knowledge of medicine and public health to educate the members of her community. She oversees the Immunization Coalition of Delaware, supporting efforts to increase Delaware’s vaccination rates for all Delawareans. She implements and educates both citizens and health care professionals on the Delaware Medical Orders for Scope of Treatment (DMOST) program, and works to normalize and clarify end-of-life conversations and treatment goals. She also works to educate people about chronic disease, healthy behaviors, and nutrition. She is a contributor to the Delaware Journal of Public Health and a member of the American Public Health Association.

**Holly Archinal** is a Research Intern at the Christiana Care Value Institute. She recently completed her post-baccalaureate premedical studies at University of Delaware. Prior to that, she was a writer and producer in sports television and independent film. She graduated from Bryn Mawr College with a BA in English Literature and has a certificate in Filmmaking from New York University. She is currently in the application process for medical school. Her area of interest is the connection of cutting-edge medical treatment to underserved populations, especially those in rural areas. She has been involved in the execution of the "Partners in Research" Chronic Kidney Disease project since June 2016.

**Alexa Meinhardt** graduated from the University of Delaware in May with a BA in Biological Sciences with minors in Psychology and Public Health. She is working as a Research Student Intern at the Value Institute at Christiana Care through the Seema S. Sonnad Memorial Fund for Young Investigators Award. Based on her interest in the social determinants of health and her passion for research, she intends to pursue a Master of Public Health with a concentration in Epidemiology. At the Value Institute Alexa has worked on different projects in several capacities, primarily two projects on opioid withdrawal. Part of her work involves assisting with planning the conference, and she is excited to have worked behind-the-scenes with the stakeholders and watched the conference evolve.
EXHIBITORS

**Christiana Care Kidney Transplant Program** offers the only adult kidney transplant program in Delaware and just recently celebrated its 10-year anniversary serving its neighbors with kidney disease. The Kidney Transplant Program provides value to more than 1,000 patients each year by providing services for evaluation, waitlist management, post-donation and post-transplant. Local patients receive excellent care and avoid the need to travel greater than an hour to Philadelphia or Baltimore for their transplant services. Call 302-623-3866 for more information or visit us at [www.christianacare.org/kidneytransplant](http://www.christianacare.org/kidneytransplant).

**Delaware Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)** is one of the eleven agencies in the Delaware Department of Health and Social Services (DHSS). The Division offers supports and services to both older adults, age 60 and over and adults, age 18 and over, with a physical disability, to allow people to live safely in the community. DSAAPD also maintains Delaware’s Aging and Disability Resource Center (ADRC) which can be reached at (800) 223-9074 or Delaware [ADRC@state.de.us](mailto:ADRC@state.de.us). The Guide to Services for Older Delawareans and Persons with Disabilities, an over 200 page guide, is available online at our web site at [www.dhss.delaware.gov/dsaapd](http://www.dhss.delaware.gov/dsaapd) and in print by calling us at (800) 223-9074.

**Dialysis Patient Citizens (DPC)** is a nationwide, non-profit, patient-led organization working to improve the quality of life for all dialysis patients through education and advocacy. We work hard developing awareness of dialysis issues, advocating for dialysis patients, promoting favorable public policy and improving the partnership between patients and caregivers. Our organization has grown to more than 29,000 members, consisting of dialysis and pre-dialysis patients as well as their family members. Our policies and our mission are guided solely by our membership. For more information, visit us at [www.DialysisPatients.org](http://www.DialysisPatients.org).
Gift of Life has worked since 1974 to coordinate life-saving and life-enhancing transplants for those waiting, while supporting the generous donors and their families who have chosen to give others a second chance through organ donation. Gift of Life is a nonprofit organization serving the eastern half of Pennsylvania, southern New Jersey and Delaware. Visit www.donors1.org for more information.

Henrietta Johnson Medical Center (HJMC) is a Federally Qualified Health Center with sites located in the City of Wilmington and Claymont Delaware. HJMC provides an all-inclusive range of Medical and Dental services for the entire family. HJMC offers caring, quality healthcare for Women, Children, Adolescents, Adults and Seniors. HJMC participates with most major insurances, including Medicaid and Medicare. HJMC provides care to individuals who are uninsured as well. People in need of health care will never be turned away from Henrietta Johnson Medical Center; as we offer a sliding fee scale, based on family size and household income, for individuals without health care insurance. For more information about HJMC, visit our website at www.hjmc.org.

National Kidney Foundation (NKF) is the largest, most comprehensive and longstanding, patient centric organization dedicated to the awareness, prevention and treatment of kidney disease in the US. We are dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by kidney disease, and increasing the availability of all organs for transplantation. For more information about NKF visit www.kidney.org.

Polycystic Kidney Disease (PKD) Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD) and to improve the lives of those it affects. We do this through promoting research, education, advocacy, support and awareness on a national level, along with direct services to local communities across the country. We are the largest private funder of PKD research. Over the last 30 years, we have invested more than $42 million in basic and clinical research, nephrology fellowships and scientific meetings with a simple goal: to discover and deliver treatments and a cure for PKD. Visit us at www.pkdcure.org for more information.
Quality Insights Renal Network 4 is the End-Stage Renal Disease (ESRD) Network for Pennsylvania and Delaware. Under the direction of the Centers for Medicare & Medicaid Services (CMS), the ESRD Network Program consists of a national network of 18 ESRD Networks, responsible for each U.S. state, territory, and the District of Columbia. Quality Insights Renal Network 4 is committed to providing healthcare professionals with support, guidance and information while also making sure people with Medicare who have been diagnosed with ESRD receive the dialysis care they need. Our foremost goal is to provide patient-focused services to the almost 18,000 beneficiaries in our Network, helping them navigate the system and take an active role in their dialysis care. Specifically, we develop standards to improve patient care; provide educational resources for patients, families and renal professionals; promote vocational rehabilitation to help patients remain working or return to the work force; support dialysis facilities and dialysis staff in resolving patient issues; assist in resolving dialysis patient grievances; and collect and report ESRD statistics. Learn more about us by visiting our website at www.qirn4.org.

University of Delaware Renal Rehab Program gives patients with Chronic Kidney Disease access to regular, supervised exercise. The program is open to Chronic Kidney Disease, Dialysis and Kidney Transplant patients. Patients are provided with an individually tailored exercise prescription with all exercise sessions monitored by a clinical exercise physiologist. If you would like to participate in the program or if you would like to refer patients on to the program please contact us on 302-831-4659 or email: kidney-disease-research@udel.edu.
Partners in Research

More than 20 million people over the age of 20 in the U.S. have Chronic Kidney Disease (CKD). Because CKD patients have multiple comorbid conditions they see numerous healthcare providers. Poor communication between physicians as well as different electronic health records systems create fragmented patient care, resulting in suboptimal clinical outcomes. A CKD registry in development in Delaware seeks to join electronic health records of multiple sources to improve coordination of care. A team of patients, clinicians, and researchers will collaborate to gather information and facilitate Patient-Centered Outcomes Research (PCOR) based on the CKD registry.

The aims of our project are to understand which outcomes and research questions patients, physicians and payers are most interested in, what additional data would be important for PCOR, and to solicit feedback on research designs, privacy issues and data sharing in the context of PCOR. This conference is the second annual conference for the Partners in Research team, and we look forward to many more as we continue to share our work and our progress driving PCOR in Delaware.

This program is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (contract number 3426 PI: Jurkovitz). The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit organization authorized by congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions.

The registry-related project work is supported by an Institutional Development Award (IDeA) from the National Institute of General Medical Sciences of the National Institute of Health under grant number U54-GM104941 (PI: Binder-Macleod).

Special thanks to Eric V. Jackson, Jr., without whose vision and inspiration this conference would not have occurred. We would also like to thank the staff of the Value Institute and the Delaware Academy of Medicine, who worked tirelessly on preparations for this conference. In particular, we would like to recognize Lisa Maturo and Yvonne Miley for their support.