

PROJECT PATIENT CARE.ORG

USING THE VOICE OF THE PATIENT TO
IMPROVE CARE IN CHICAGO AND BEYOND



Greetings!

Project Patient Care (PPC) is grateful to work with so many amazing patients, families, caregivers, healthcare providers, and organizations that are devoted to improving health and healthcare.

In this issue, we have articles on:

- Announcing and celebrating our Champion Change Agents series
- April 10th webinar with principals of the national ACHIEVE program for consumers and providers on Innovations in Care Transitions hosted by PPC
- New national direction and transformation and support for chronic kidney disease and end stage renal disease
- Identifying more opportunities for patients, families, and caregivers to have an influence on what is most important to consumers
- Remembering Bob Malizzo, who helped to pave the way with his wife, Barb, for the voice of the family to be heard after the tragic loss of their daughter to a medical error
- West Health Livestreaming national event - "High Costs, Broken Promises: Healthcare in America Summit" on Tuesday, April 2. All sessions will be broadcast live from 8:15 a.m. to 2:15 p.m. Central time

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." Margaret Mead



MARY BALIKER
National Kidney Foundation Advocate
LIVE LAUGH LOVE



PRECIOUS McCOWAN
BS, MS, ESRD Network of Texas



BOBBIE REED
National Kidney Foundation Advocate

Champion Change Agents

CHAMPION CHANGE AGENTS

Each month we will be celebrating Champion Change Agents -- people that are passionate about making a difference and are having a major impact on health and healthcare. PPC will be hosting a podcast each month in which the Champion Change Agent will share their story and how we all can by working together have a positive impact on health and healthcare.

Starting off our series in March 2019, we wanted to recognize both National Kidney and Women's History Month and have three extraordinary women we are celebrating – Mary Baliker, Precious McCowan, and Roberta ‘Bobbie’ Reed. These three women have been dramatically impacted by CKD. They or a family member were diagnosed with CKD and end stage renal disease (ESRD) when they were under the age of 30 and were placed on dialysis and have had one or more kidney transplants.

Their journey has been remarkable as they have faced CKD and end stage renal disease and have become advocates for themselves and others. Many people in the kidney disease community will recognize them as their voices have carried from local and state kidney disease organizations to national levels. They have become advocates for increasing and improving CKD screening; improvements in in-center dialysis and home dialysis; increasing organ donations for kidney transplants; and innovations in CKD and ESRD treatment.

You will not want to miss hearing about the remarkable journeys of Mary, Precious, and Bobbie – *they truly are Champion Change Agents! We will be sending you a link to their podcast this week for you to learn to and share with others.*

IMPROVING PATIENT CARE TRANSITIONS WEBINAR **Wednesday, April 10 from 1:00 - 2:00 p.m.**

Learn what makes for a great experience and outcome for patients that are transitioning from hospital to nursing home, home health, community services, and home. For the past few years, the University of Kentucky has been leading a national initiative on care transitions under an award from PCORI (Patient-Centered Outcomes Research Institute).

Known as Project ACHIEVE (Achieving Patient-Centered Care and Optimized Health In

Care Transitions by Evaluating the Value of Evidence), this landmark study identifies successful care transition strategies in a patient-centered care environment. The webinar will highlight the results of the focus group and retrospective findings.

Guest Presenters will include:

- Dr. Glen Mays, Professor of Health Services and Systems Research in the Department of Health Management and Policy, Director of the Systems for Action Research Program, founding director of the National Public Health Practice-Based Research Networks (PBRN) Program, University of Kentucky
- Dr. Mark Williams, MD, MHM, FACP. Chief Quality & Transformation Officer, Chief Division of Hospital Medicine, Vice Chair of Department of Internal Medicine, Director of Center for Health Services Research, University of Kentucky, or
- Dr. Jing Li, MD, MS, Associate Director of the Center for Health Services Research, Director of the Office for Value & Innovation in HealthCare Delivery, University of Kentucky

Please join the free webinar meeting from a computer, tablet or smartphone.

<https://global.gotomeeting.com/join/806835021>

You can also dial in using your phone.

United States: 1 (224) 501-3412

Access Code: 806-835-021



More than 1 in 7
15% of US adults are
estimated to have chronic
kidney disease, that is about
30 million people.

NEW DIRECTION and TRANSFORMATION

Chronic Kidney Disease and End Stage Renal Disease

In response to the increasing number of patients diagnosed with chronic kidney disease (CKD) at a late stage, the Department of Health Human Services (DHHS) and its agencies and departments are taking on new strategic approaches and programmatic changes to address the

increase among the United States population. Prompted by the National Kidney Foundation and advocates such as our Champion Change Agents and others, there is a growing awareness of the challenges our nation faces if it does nothing to raise awareness and provide support for people with early stages of kidney disease.

During National Kidney Month, DHHS Secretary Alex Azar II spoke at the National Kidney Patient Summit and DHHS Deputy Secretary Eric Hargan spoke at Datapalooza highlighting the transformation that needs to occur with chronic kidney disease. The transformations include increased focus on prevention and detection; improved outcomes of dialysis; increasing shift and incentives to home dialysis rather than in-center dialysis; increasing organ donations for kidney transplants; and innovative approaches to managing CKD.

Background. There are five stages of kidney disease with stages 1 -3 with no specific symptoms; noticeable changes at CKD Stage 4; and at Stage 5 a patient is in kidney failure and requires dialysis or a transplant. CKD is a progressive disease but with interventions,

patients can maintain their stage. There is no cure for CKD, so one can go up or stay at a CKD stage, but cannot go down to a lower stage.

Diagnosis. According to the Centers for Disease Control and Prevention (CDC), 9 in 10 adults don't know they have CKD and 1 out 2 people with very low kidney function and should be on dialysis, do not know they have kidney failure.

In order to address this lack of awareness of CKD, DHHS is increasing the awareness campaign and will have Quality Innovation Network - Quality Improvement Organizations (QIN-QIO) working to increase awareness and testing starting in July 2019.

Testing. There are two tests that can detect CKD. A blood test measures how much blood your kidneys filter each minute, which is known as your glomerular filtration rate (GFR). A urine test checks for albumin in your urine. Albumin is a protein that can pass into the urine when the filters in the kidneys are damaged. A healthy kidney does not let albumin pass into the urine. These tests should be administered at same visit and will result in identifying if a patient has CKD and if they do, it will identify the CKD stage.

Causes. The two leading conditions linked to CKD are diabetes and hypertension and according to the CDC, these two conditions are linked to 3 out of 4 new kidney failures. Other conditions or risk factors linked to CKD are heart disease, family history of CKD, and obesity.

Data. There are many sources of data that can be utilized to understand CKD within your community, state, and nation. Below are some of the sources that are publicly available at no charge:

United States Renal Data System - 2018 Annual Report available; extensive data at a state level by many variables; projections for 2030 - [USRDS web site](#)

Centers for Disease Control and Prevention (CDC) - National data and information by reporting states; infographics; consumer, patient, and provider information - [CDC Web Site](#)

Centers for Medicare and Medicaid Services and Office of Minority Health - Mapping Medicare Disparities including CKD by county and patient characteristics [MMD Web Site](#)

- Most state public health and Medicaid agencies are tracking CKD and ESRD data. Check with the state agencies for current information as many states may vary from national norms based upon health of population. For example, in Illinois approximately 50% of the patients on dialysis are 65 years and older and 50% patients on dialysis are 64 years and younger. In Chicago, 62% of the patients on dialysis are black, yet blacks make up a little less than 30% of the Chicago population.

The National Kidney Foundation provided the current national information below on the state of CKD and ESRD on March 4, 2019 at the National Kidney Patient Summit as DHHS Secretary Azar spoke on transforming kidney care:

"In the United States 30 million adults are estimated to have chronic kidney disease—and most aren't aware of it. 1 in 3 American adults are at risk for chronic kidney disease. Risk factors for kidney disease include diabetes, high blood pressure, heart disease, obesity and family history. People of African American, Hispanic, Native American, Asian or Pacific Islander descent are at increased risk for developing the disease. African Americans are 3 times more likely than Whites, and Hispanics are nearly 1.5 times more likely than non-Hispanics to develop end stage renal disease (kidney failure).

Nearly 680,000 Americans have irreversible kidney failure, or end-stage renal disease (ESRD), and need dialysis or a kidney transplant to survive. More than 475,000 ESRD patients receive dialysis at least three times per week to replace kidney function. Nearly 100,000 Americans are on the waitlist for a kidney transplant right now. Depending on where a patient lives, the average wait time for a kidney transplant can

be upwards of three to seven years. Living organ donation not only saves lives, it saves money. Each year, Medicare spends \$87,000 per dialysis patient and less than half, \$32,500, for a transplant patient."

The Future. According to a recent study, "Projecting ESRD Incidence and Prevalence in the United States through 2030" in the January 2019 Journal of the American Society of Nephrology, by 2030, there will be an increase of patients with ESRD ranging from 29% to 68% or 971,000 patients to 1,259,000. This estimate is based upon present prevention and detection approaches and a reduction in ESRD deaths due to improved treatments. The full study is available at "Projecting ESRD Incidence and Prevalence in the United States through 2030" Keith P. McCullough, Hal Morgenstern, Rajiv Saran, William H. Herman, Bruce M. Robinson, JASN Jan 2019, 30 (1) 127-135; DOI: 10.1681/ASN.2018050531.

Cost of Care. According to DHHS, in 2016 Medicare spent up to \$113 billion on CKD and ESRD with \$79 billion to cover patients with CKD and \$34 billion on patients with ESRD. The \$113 billion represents more than one in five Medicare dollars spent on CKD and ESRD. CMS is intent on reversing these trends through prevention, early diagnosis and interventions, and in-home and innovative approaches to ESRD treatments.

We hope the Champion Change Agents and this newsletter article prompt you to obtain your CKD Score and to spread the word about the importance of CKD screening to family and friends.

Opportunities for Patients, Families, Caregivers and Consumers to be Involved

PPC often hears about opportunities for patients, families, and caregivers to get involved in research, measurement development, or sharing their story. We would like to make you aware of these opportunities as they become available.

CMS Technical Expert Panels. CMS has three Technical Expert Panels (TEP) they are recruiting for and are interested in having patient, family, or caregiver participants on the TEP. The three TEPs and the nomination deadline are listed below:

- End Stage Renal Disease (ESRD) Dialysis Facility Compare (DFC) Star Ratings - April 5, 2019 nomination deadline
- MACRA Episode-Based Cost Measures - Call for Wave 3 Clinical Subcommittee Nominations - April 12, 2019 nomination deadline
- 2019 Merit-based Incentive Payment System (MIPS) Improvement Activities (IA) Technical Expert Panel (TEP) - April 26, 2019 nomination deadline

To find out more about the CMS TEPS and how to apply to be a patient participant, [Click Here](#)

Congratulations to those that responded to the last call to action for patients, family members, and caregivers and were able to participate in the National Quality Forum Annual Conference and the upcoming PCORI programs.



BOB MALIZZO

Robert "Bob" Malizzo, a patient safety advocate well known to the Hospital Improvement Innovation Network (HIIN) community, passed away on March 14, 2019. He, his wife Barb, and daughter Krissy, have been active in the Partnership for Patients campaign from the beginning.

Bob came to patient safety after the loss of his oldest daughter, Michelle, the mother of two young children, to an anesthesia event. During a keynote at the CMS 2011 Quality Conference, Bob and Barb shared their thoughts about the healing power of open, honest communication following medical error and how it restored their trust. They went on to work with leaders at UI Health in Chicago, the hospital where Michelle died, to change anesthesia standards. Bob and Barb also served on the UI Health committee that does root cause analyses of patient safety events, where they were known as "the conscience of the community."

Bob was a US Army veteran, who over the course of his life also served as a police officer, a deputy sheriff, and the mayor of Hobart, IN. An award given by CMS for his HIIN work was proudly displayed at his funeral, testifying to the dedication of Bob and the whole Malizzo family to helping our HIIN community ensure safety and prevent harm in healthcare.

Despite their deep grief and pain when their daughter Michelle died, they donated her organs. One of the recipients of Michelle's directed donation of a kidney spoke at Bob's service - very moving as he reflected on the gift Michelle and the Malizzo family gave him.

The interview below is from our February 2017 Project Patient Care Newsletter with Bob and Barb Malizzo:

"Bob and Barb Malizzo continue to share the story of their beloved daughter Michelle, so that we can all learn to listen to and honor the voice of the patient.

Many of us were first introduced to Bob and Barb Malizzo in December 2011 at the CMS Quality Conference as they shared the story of their daughter, Michelle, who died due to an avoidable medical error. While it was very painful for them to share their story, they hoped that by sharing their experience others would learn from it and speak up and listen to the voice of the patient and family.

In their December 2016 presentation at CMS Quality Conference they shared the story of Michelle, a loving mother, wife, daughter, sister, and friend to many. They also shared how Michelle would have been so happy to learn about the quality and safety advances in health care over the past 6 years. Michelle would also have been happy to know that her mom and dad were helping others avoid errors through their sharing of their experience.

Since 2011, Bob and Barb have been appointed to a hospital committee where they actively review safety and quality issues and are part of a hospital team making recommendations for improvement. They also have crisscrossed the entire nation sharing in large and small group settings their experiences and how best an organization can integrate patients and families into their organizations.

Project Patient Care (PPC) posed a few questions to Barb and Bob Malizzo to gain some insight into their experience and thoughts since the death of Michelle.

PPC: What do you want us all to know about your daughter, Michelle?

Bob and Barb: "Michelle was a loving and giving person. She was concerned about the little guys, She always gave to different organization like Food Pantries, Goodwill, March of Dimes, St. Judes, and any more. She loved being a mother and loved politics. She was President of the Portage Chamber of Commerce, and loved playing Darts at the local Moose Lodge. She was a people person."

PPC: The loss of Michelle was a catastrophic event. Why did you decide to share your painful story to health care providers and other patients and families?

Bob and Barb: "We share our story because that is what Michelle would want. Always for the little guy. We felt that healthcare had to change and we knew we had to help in whatever small way we could. Knowing no one should experience what we did. Hospitals are supposed to be a safe zone not a harm zone. It also helped us heal to share our family story."

PPC: You often times mention that the hospital did not try to make excuses, but stepped up right away to help Michelle's family through this catastrophic event. How did the way in which the hospital addressed the loss of Michelle effect you and your family?

Bob and Barb: "The Hospital being honest with us helped us understand what happened, but it didn't stop the anger we felt, in retrospect it helped start the healing process, Without the truth we probably would still be angry, and bitter towards healthcare."

PPC: To this day, you always volunteer to share your experience and provide a perspective on why patients, families, and providers need to work together to prevent events. How do you find the strength to keep doing what you do so well?

Bob and Barb: "We find strength in sharing our story knowing that it may help others; that Michelle didn't die in vain. That maybe doing what we do will change healthcare making it safer and more engaging with patients. We also hope that hospitals and caregivers will be trusted again by being open and honest."

There is no doubt that Michelle is proud of her parents as they selflessly spread the word that the voices of patients and families can make a difference and in some instances, it can mean the difference between life and death.

Take three minutes out of your day to listen to Barb and Bob as they recount their experience and also extend special thanks and appreciation to all the providers and patient advocates that have worked to improve quality and safety over the past six years.

To view the three-minute video - Clich [Here](#)

"HIGH COSTS, BROKEN PROMISES: HEALTHCARE IN AMERICA SUMMIT"

Tuesday, April 2 Live Webinar from 8:15 a.m. to 2:15 p.m. Central Time

West Health hosts a national event with insightful and leading speakers addressing the costs of care. Presenters include policy makers, elected officials, media, providers, patients, families, caregivers, and more. To register for the free, national livestreaming event, [click here](#)

PPC STAFF COMMUNITY ENGAGEMENT - MAKING A DIFFERENCE



Marty Hatlie with World Health Organization members discussing patient safety and global resolution on patient safety.



Pat Merryweather and Laura Allen of PPC meeting with Congresswoman Laura Underwood at PPC Office in Chicago.



Pat Merryweather at Bharathi Theertha Event Celebrating World Water Month - Pat received a Water Warrior award for water and sanitation work in India, Nigeria, and Kenya.

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We Love to Hear From You!

We are always happy to hear from you - please feel free to contact us at any time.
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Thank you