



pair
Palliative and Advanced
Illness Research Center

Annual Report 2018

Mission

We generate high-quality evidence to advance healthcare policies and practices that improve the lives of all people affected by serious illness.

Vision

Patients with serious illness spend more of their time pursuing life goals outside of health care settings.

Health system leaders and clinicians have the real-world evidence necessary to implement interventions that improve patient outcomes.

Payers have high-quality data upon which to base coverage decisions, thereby promoting high-value service provision for patients with serious illness.

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Letter From the Director



I'm happy to share PAIR's Annual Report for the 2018 calendar year.

Two years ago, we set out to establish our presence in the serious illness care research space, building on our reputation as leaders in conducting innovative work to understand end-of-life decision making. We dedicated ourselves to designing research that placed the outcomes important to seriously ill patients, caregivers, clinicians, health systems, and payers at the center of our work, with a focus on generating high-quality evidence. At the same time, as a new center, we prioritized listening to our advisors and stakeholders, who asked us, "How will the world be different if the Center fulfills its mission?" What we heard - and what our work to date makes clear - is that our efforts to work with the nation's largest health systems and insurers, and our ability to apply diverse methodological approaches in the design and testing of scalable interventions, fills a critical gap. Leadership in real-world research, conducted in the everyday settings where seriously ill patients receive their care, is where our field's most pressing needs remain. Our team continues

to amass the practical experience to deliver on this mission.

The year's milestones speak volumes: We wrapped recruitment for the largest-ever prospective study in palliative care across 11 Ascension hospitals; launched a pragmatic trial of two electronic health record interventions designed to increase ICU clinicians' engagement in comfort-oriented approaches to care within 19 ICUs across Atrium Health; and continued to apply cutting edge, data science approaches to problems in the delivery of serious illness

include palliative care, racial disparities, and end-of-life decision-making among patients with chronic kidney disease; and Dr. Joanna Hart, MD, MS, a pulmonary and critical care physician whose research interests include empirical bioethics, patients' formation of expectations for their health, and physician-attributable variation in care delivery.

Looking ahead to the upcoming year, we'll build on our roster of large health system partners, starting with our leadership on a new collaboration between Penn Medicine, Geisinger Health, Kaiser Permanente

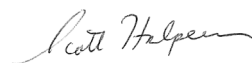
Leadership in real-world research, conducted in the everyday settings where seriously ill patients receive their care, is where our field's most pressing needs remain.

care here in our own health system. We also launched our signature pilot project program to propel the research ideas of Penn Medicine clinician teams on the front-lines of serious illness care delivery; you can learn more about this partnership on page 12.

We forged ahead on our commitment to build the infrastructure needed to improve serious illness care in the real world by establishing the pipeline of future leaders. In 2018, we welcomed several talented faculty members whose work you'll read about in this report: Dr. Norma Coe, PhD, a health economist whose research focuses on the financing and delivery of long-term and end-of-life care; Dr. Amaka Eneanya, MD, MPH, a nephrologist whose research interests

Southern California, and Henry Ford Health System, supported by \$11.2 million in funding from the Patient-Centered Outcomes Research Institute (PCORI). We're privileged to have the opportunity to engage a number of patient, community organization, policy, insurer, and health system leadership partners on this newly funded project.

We have a lot to look forward to in 2019. As our partnerships grow, so too does our potential for impact and our ability to improve the lives of patients and caregivers facing serious illness.



Scott Halpern, MD, PhD

Leadership

External Advisory Board

Susan Block, MD Senior Advisor, Serious Illness Care Program, Ariadne Labs; Co-Director, Harvard Medical School Center for Palliative Care; **Ziad Haydar, MD, MBA** Senior VP and Chief Clinical Officer, Ascension; **Maureen Henry, JD, PhD** Research Scientist, National Committee for Quality Assurance; **Shari Ling, MD** Deputy Chief Medical Officer, Centers for Medicare and Medicaid Services; **Diane Meier, MD** Director, Center to Advance Palliative Care; **BJ Miller, MD** Palliative Care, University of California, San Francisco; **Arnold Milstein, MD, MPH** Director, Stanford Clinical Excellence Research Center; **Barry Ostrowsky, JD** President and Chief Executive Officer, RWJBarnabas Health; **Richard Snyder, MD** Senior VP and Chief Medical Officer, Independence Blue Cross; **B. Vindell Washington, MD, MHCM** Senior VP and Chief Medical Officer, Blue Cross and Blue Shield of Louisiana



Internal Advisory Board

Patrick J. Brennan, MD Senior VP and Chief Medical Officer, UPHS; **Regina Cunningham, PhD, RN, FAAN** Chief Executive Officer, HUP; **Risa Lavizzo-Mourey, MD, MBA** University Penn Integrates Knowledge Professor (PIK) of Health Policy and Health Equity, University of Pennsylvania; **Kevin Mahoney, MBA** Executive VP and Chief Administrative Officer, UPHS; **Ralph Muller, MA** Chief Executive Officer, UPHS; **Mary D. Naylor, PhD, RN, FAAN** Director, NewCourtland Center for Transitions and Health; **Michael Parmacek, MD** Chair of Department of Medicine, University of Pennsylvania; **Lynn Schuchter, MD** Chief of Division of Hematology-Oncology, University of Pennsylvania



Steering Committee

Michael Cella Associate Chief Operating Officer, Department of Medicine; **Elizabeth Cooney, MPH** Director of Research Operations, PAIR Center; **Scott Halpern, MD, PhD** Director, PAIR Center; **Vanessa Madden** Assistant Director for Project Management, PAIR Center; **Mark Mikkelsen, MD, MSCE** Chief, Section of Critical Care Medicine, Pulmonary, Allergy, & Critical Care; **Mark Neuman, MD, MSc** Director, Penn Center for Perioperative Outcomes Research and Transformation; **Nina O'Connor, MD** Director of Palliative Care, UPHS



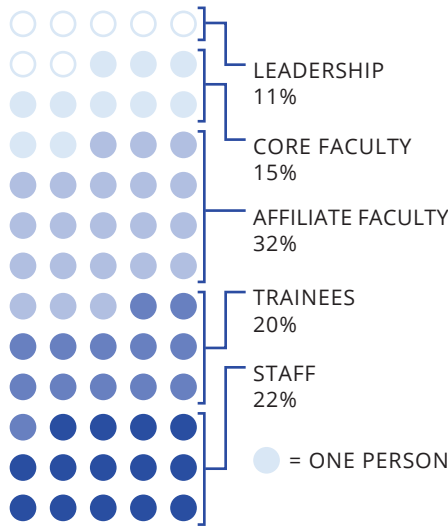
Our Partners



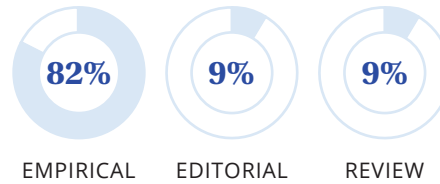
2018

At a Glance

NUMBER OF PEOPLE AT THE PAIR CENTER = **65**



ARTICLES PUBLISHED THIS YEAR CONSISTED OF:



PUBLISHING INCREASED

162%

COMPARED TO LAST YEAR

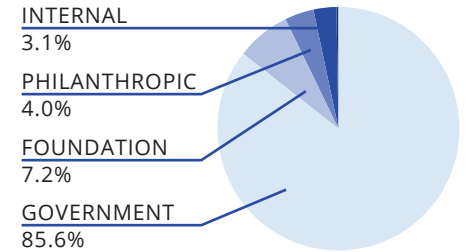


CUMULATIVE RESEARCH FUNDING INCREASED BY

270%

OVER THE PRIOR YEAR

BRINGING TOTAL FUNDS* TO **\$38,932,515**



Awards and Recognition

Norma Coe, PhD

Appointed Analysis Core Co-Director on recently awarded National Institute on Aging Center for Improving Care Delivery for the Aging (CICADA)

Kate Courtright, MD, MSHP

Awarded K23 Career Development grant from National Institutes of Health (NIH)

Amaka Eneanya, MD, MPH, FASN

Inducted into the American Journal of Kidney Disease Reviewer Hall of Fame

Michael Harhay, PhD, MPH

Named Statistical Editor of the Annals of the American Thoracic Society
Received Tyroler Student Prize Paper Award from the Society for Epidemiologic Research

Joanna Hart, MD, MSHP

Received the American Thoracic Society Early Career Achievement Award
Named to editorial board of Medical Decision Making

Meghan Lane-Fall, MD, MSHP

Selected for induction into the American College of Critical Care Medicine
Named to the Editorial Boards of Anesthesiology and Anesthesiology and Analgesia

Meeta Prasad Kerlin, MD, MSCE

Awarded American Thoracic Society Foundation unrestricted grant in Critical Care
Appointed Chair of Program Committee for American Thoracic Society's Behavioral Science Assembly
Awarded R03 and R01 Research Grants from NIH

Gary Weissman, MD, MSHP

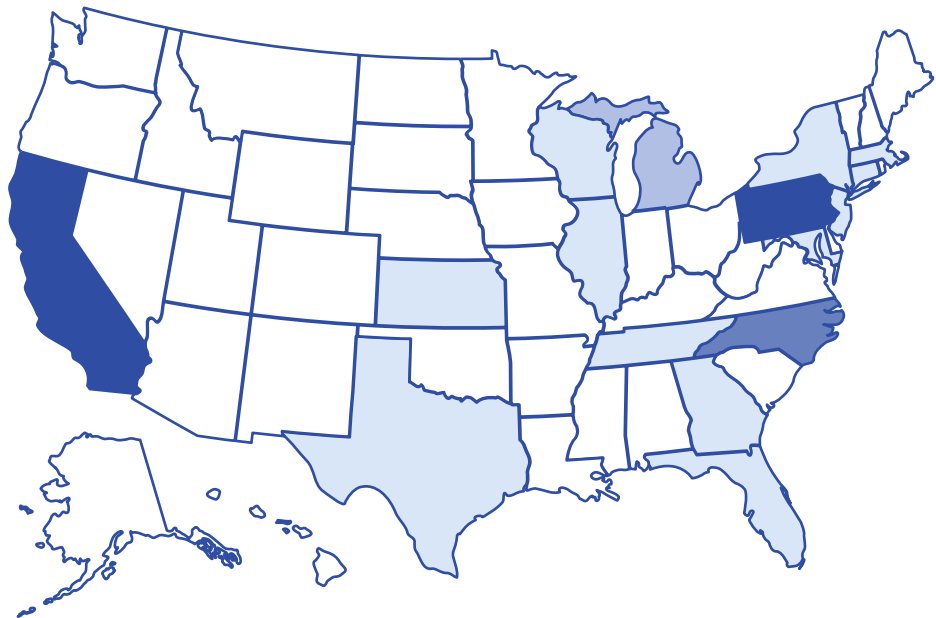
Awarded K23 Career Development grant from NIH

106

COLLABORATING
RESEARCH SITES
ACROSS THE USA



NUMBER OF
INTERNATIONAL = 4
RESEARCH SITES



*Industry funds account for less than 1% of total

Notable Publications

MDM Policy & Practice

Josephs M, Bayard D, Gabler NB, Cooney E, Halpern SD.
Active choice intervention increases advance directive completion: A randomized trial.

Critical Care Medicine

Halpern SD.
Using default options and other nudges to improve critical care.

Journal of General Internal Medicine

Kohn R, Harhay MO, Bayes B, Mikkelsen ME, Ratcliffe SJ, Halpern SD, Kerlin MP.
Ward capacity strain: A novel predictor of 30-day hospital readmissions.

Journal of the American Geriatrics Society

Coe NB, Skira MM, Larson EB.
A comprehensive measure of the costs of caring for a parent: Differences according to functional status.

Journal of Critical Care

Detsky ME, Kohn R, Delman AM, Buehler AE, Kent SA, Ciuffetelli IV, Mikkelsen ME, Turnbull AE, Harhay MO.
Patients' perceptions and ICU clinicians predictions of quality of life following critical illness.

Annals of Internal Medicine

Weissman GE, Kerlin MP, Yuan Y, Gabler NB, Groeneveld PW, Werner RM, Halpern SD.
Population trends in intensive care unit admissions in the United States among Medicare beneficiaries, 2006 – 2015.

Project Milestones

Here we highlight important milestones across 5 new and ongoing projects among the more than 25 active projects led by our core faculty and trainees. To learn more about our current research efforts, go to pair.upenn.edu/projects.



Randomized Evaluation of Default Access to Palliative Services (REDAPS) trial

Funding: National Institute on Aging

The Randomized Evaluation of Default Access to Palliative Services (REDAPS) trial aims to provide real-world evidence on the effects of inpatient palliative care services across clinical, patient-centered, and economic outcomes. Implemented across 11

Ascension Hospitals, the trial concluded in November 2018 after enrolling more than 30,000 seriously ill patients, making it the largest prospective study ever conducted in palliative care. In 2019, the research team, led by Director Scott Halpern and Dr. Kate Courtright, will finalize analyses and deliver the evidence to payers and policy makers invested in whether specialty inpatient palliative care services deliver on their great potential to improve quality and/or control costs.

Behavioral Economic Interventions to Improve Care Quality for Mechanically Ventilated Patients

Funding: ATS Foundation Research Grants

This mixed-methods study, led by Core Faculty Dr. Meeta Prasad Kerlin, explores the perceived benefits and barriers to different behavioral economics-based strategies embedded in electronic health records to promote use of lung protective ventilation (LPV) -- a strategy that has been shown to improve survival, reduce duration of mechanical ventilation (MV), and reduce organ failure among patients who have acute respiratory distress syndrome (ARDS). In 2018, Dr. Kerlin and PAIR researchers completed semi-structured interviews of clinician stakeholders, with manuscript submissions underway. Working with the UPHS Information Services, the research team also made progress in designing two novel order sets for initiation of invasive MV based on behavioral economic strategies in the health system's EHR. The preliminary data from this project informed a successful NHLBI-funded R01 proposal for a pragmatic trial within the 6-hospital health system that Dr. Kerlin will lead beginning in 2019.

ABOVE: Meeta Prasad Kerlin, MD, MSCE

RIGHT: Project Manager Erich Dress, MBE, MPH presents PONDER-ICU data

The Ethical Acceptability of Deception in Physician-Patient Communication

Funding: Greenwall Foundation, Roybal Center on Behavioral Economics and Health, National Institute on Aging

Led by Core Faculty Dr. Joanna Hart, this study aims to quantify how seriously ill patients, surrogate decision makers, and physicians who care for seriously ill patients view beneficent deception by physicians, or the practice of providing overly optimistic information to patients in efforts to promote their hope and well-being. The study will generate empirical data integral to shaping clinical practice and policies for physicians communicating with patients. The research team successfully reached its targeted enrollment of over 300 physicians, caregivers, and patients. In the process, PAIR researchers forged an important new partnership with Lancaster General Health, affording the Center the opportunity to recruit patients not well-represented in the rest of the University of Pennsylvania Health System (UPHS) and expand its geographic reach in the Pennsylvania region.

Automated Machine Learning for Prediction of 6-month Mortality Among Patients in the Intensive Care Unit

Funding: Philanthropic support to the PAIR Center

Leveraging data on nurses' and physicians' predictions of clinical outcomes from our Patient-Centered Outcomes Prognostication (PCOP) study (Detsky, JAMA 2017), this secondary analysis led by Dr. Gary Weissman compares the relative performance of various types of machine learning algorithms and intensive care unit (ICU) physician and nurse predictions of long-term outcomes among critically ill patients admitted to 5 ICUs across 3 hospitals at Penn. The research team is currently in the process of training the machine learning models, and will hold an internal Data Science Competition to see which models perform best. The project highlights the PAIR Center's burgeoning partnership with the Institute for Biomedical Informatics, the interdisciplinary hub of informatics scholarship at Penn, and explores previously unanswered questions about optimal prediction modeling strategies among seriously ill patients.



Prognosticating Outcomes and Nudging Decisions with Electronic Records in the ICU (PONDER - ICU)

Funding: The Donaghue Foundation

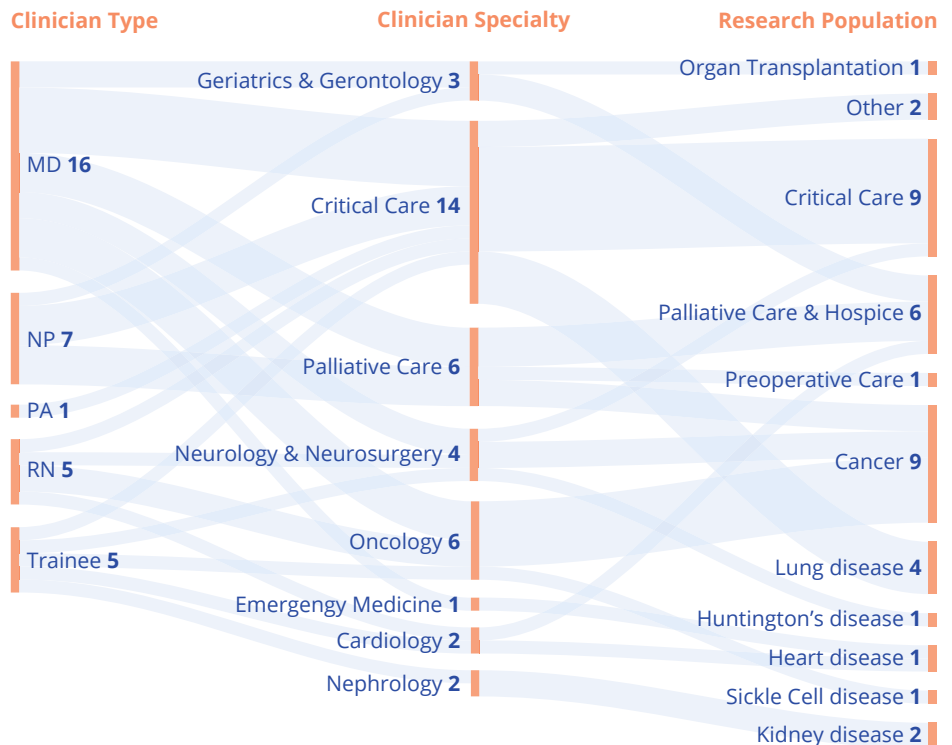
The PONDER-ICU trial seeks to demonstrate how simple and scalable electronic health record (EHR) interventions rooted in behavioral economics may improve patient-centered care in the ICU. A pragmatic, stepped-wedge cluster randomized trial, PONDER-ICU is the PAIR Center's first collaboration with Atrium Health (formerly Carolinas HealthCare System). With leadership from Core Faculty Dr. Kate Courtright, the research team completed the validation and launch of the EHR-based algorithm to identify eligible trial participants and trigger delivery of the trial's EHR-based interventions to clinicians in real time. The study entered its control phase at all of the study's 10 Atrium hospitals in February 2018, and has enrolled approximately 1,000 patients to date.

PAIR with PAIR

Pilot Program

In 2018, the Center established the Pitch An Idea for Research with PAIR (PAIR with PAIR) Pilot Program with support from UPHS. The ultimate goal of this ongoing pilot program is to bring new perspectives on how to solve real-world problems faced by clinicians, patients, and caregivers to inform serious illness care research at Penn Medicine. The novel program offers non-research clinicians the opportunity to partner with our trained research team.

The inaugural applicant cycle yielded 38 applications from a diverse pool of clinicians representing 8 clinical areas within UPHS. Clinicians proposed new and understudied patient, caregiver, and clinician-directed interventions to be tested across an array of treatment settings and patient populations.



Awardees

Study of Therapeutic Exercise in Acute Respiratory Failure to Improve Neuromuscular Disability (STAND)

Critical care physician Dr. William Schweickert, and critical care nurse strategist, Dr. Juliane Jablonski, will test an early mobility intervention among mechanically ventilated patients in 14 ICUs across UPHS.



Improving the Quality and Frequency of Advance Care Planning Among Hospitalized Patients

Dr. Chris Jones, a palliative care physician, will aim to improve the quality and frequency of advance care planning among patients admitted to the Hospital of the University of Pennsylvania, leveraging the Our Care Wishes online platform, a low-cost, scalable tool built and tested by PAIR faculty in collaboration with an interdisciplinary team at Penn's Center for Health Care Innovation.



Other Penn Health System Initiatives

The motivation behind PAIR with PAIR extends beyond the recently launched pilot program to the Center's growing roster of System-wide partnerships. The following two projects highlight the Center's progress in meeting the need for responsive research support to evaluate recently deployed serious illness care programs in our health system.



ABOVE: Nina O'Connor, MD

Palliative Connect

A broad aim of the Center's work is to develop innovative solutions to tackle some of the core challenges facing the palliative care workforce, whose service demands have surged well beyond the field's capacity. In an effort to more effectively allocate scarce palliative care clinicians' services, PAIR researchers have partnered with the UPHS Palliative Care Program, led by Program Director and PAIR Steering Committee Member Dr. Nina O'Connor, and the Penn Medicine Data Science team. Together, they developed and are now testing "Palliative Connect," a predictive analytics-driven platform that seeks to identify patients most likely to benefit from palliative care. The platform uses an EHR algorithm to mine clinical data on recently admitted patients and curates a list of those who are at the highest risk of dying within 6 months. Patients meeting certain risk thresholds are triggered to receive palliative care consults automatically unless the patient's primary clinicians choose otherwise.

Following a successful pilot test of the program at the Hospital of the University of Pennsylvania (HUP), the Palliative Connect team launched a study in two UPHS hospitals in June 2018 and concluded data collection in December 2018. In 2019, the research team will complete analysis and manuscript submissions, while also finalizing the design for a larger randomized trial. An embedded, mixed-

methods study, led by Dr. Kate Courtright and PAIR researchers, recently wrapped data collection as well. This complementary study will yield important insights into patient, caregiver, hospitalist, and palliative care clinician perspectives on triggered palliative care consultation.

Advanced Heart Care at Home

Advanced Heart Care at Home is a specialized, home-based program for advanced heart failure (HF) patients, developed by the Palliative Care and

There are a growing number of serious illness care initiatives at Penn in need of evaluation.

Dr. Nina O'Connor

Cardiology Programs alongside the UPHS Center for Health Care Innovation. In 2018, the PAIR Center agreed to be the evaluative lead for this novel program, and launched a rigorous evaluation of the program at three UPHS hospitals. This work also applies behavioral economic approaches to encourage physicians to condone their patients being approached by the program's nurse. The teams aim to evaluate clinical, utilization, and cost outcomes among high-risk HF patients at the end of life, with the goal of informing future directions of the program, including translation to other illnesses.

Faculty Spotlight

New faculty member Amaka Eneanya, MD, MPH, FASN sheds light on her research interests.



ABOVE: Amaka Eneanya, MD, MPH, FASN

RIGHT: Gretchen Schwarze, MD, MPP speaks at The PAIR Center Series

How did you become interested in research at the intersection of nephrology, treatment decision-making, health disparities, and palliative care?

During my internal medical residency training, I was intrigued with the physiology of the kidneys, and was also drawn to the complex care of seriously ill patients with kidney failure. In particular, it was apparent that racial minority patients were disproportionately afflicted with the disease. This was a subject that I was passionate about given my clinical experiences at Meharry Medical College where the school's mission was to serve disadvantaged patients. My first year in fellowship was an intense clinical experience including inpatient rotations in critical care nephrology. My interest in investigating end-of-life decision-making was augmented during these intensive care unit rotations as I observed how unprepared many patients with kidney disease were to discuss their end-of-life care preferences and also engage in advance care planning. Furthermore, I observed racial and cultural differences in terms of patient knowledge, communication of preferences, and treatment decision-making.

How does your current research aim to address barriers to informed treatment decision-making among patients with advanced chronic kidney disease?

I am currently developing patient-centered and culturally sensitive educational strategies to empower patients with advanced chronic kidney disease to make decisions about treatments for end-stage renal failure that are aligned with their goals and values. These strategies are being informed by qualitative interviews with clinicians, patients, and their caregivers. This education will also help patients better communicate their care preferences for treatment with their loved ones and clinicians as well as engage in advance care planning early in the disease course.

What are some future directions for your work?

My preliminary work has demonstrated that many principles of palliative care are not routinely applied in the care of seriously ill patients with kidney failure. I hope to use data from this pilot project to inform the development of a comprehensive nephrology care program that will focus on symptom management, advance care planning, caregiver support, and outpatient palliative care access for frail and elderly patients with advanced chronic kidney disease. My goal is that patients from underserved backgrounds will have equal access to this comprehensive care program to decrease existing health disparities in nephrology.

The PAIR Center Series

The PAIR Center Series features clinicians, scholars, and health system and thought leaders at the forefront of advanced illness care. In 2018, speakers delved into topics spanning palliative care quality and advance care planning initiatives, payment reform, and community-based approaches to serious illness care. For the 2018-2019 academic year, the Center's series switched times to align with the UPHS Palliative Care Program's Grand Rounds to maximize accessibility to the talks and generate a larger, UPHS-wide conversation about some of the field's most exciting work.



2018 - 19 Academic Year Speakers



SEP 18 2018

Kate Courtright, MD, MSHP

Instructor of Pulmonary, Allergy & Critical Care
University of Pennsylvania



OCT 16 2018

Rebecca Brown, MD, MPH

Assistant Professor of Medicine
University of Pennsylvania



NOV 06 2018

Gretchen Schwarze, MD, MPP

Associate Professor of Surgery & Bioethics
University of Wisconsin



FEB 19 2019

Kimberly Johnson, MD

Associate Professor of Medicine
Duke University



MAR 19 2019

Fabian Johnston, MD, MHS

Associate Professor of Surgery
Johns Hopkins University



MAY 07 2019

David Bekelman, MD, MPH

Associate Professor of Medicine
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Penn Medicine