

**PROJECT
PATIENT
CARE**·ORG

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



Project Patient Care Newsletter - November 2019

Project Patient Care: Bringing the voice of the patient, family, and caregiver to improve health and healthcare locally, nationally, and globally.

As we enjoy the holidays, we extend our special thanks and gratitude to the healthcare providers and caregivers that provide the round the clock support and services -- and are there to meet the needs of their patients and communities. We also thank the patient advocates and partners that have stepped up to work with healthcare providers to improve health, outcomes, and experiences for all patients.

And this month, as has been done for almost two decades, we are celebrating National Family Caregiver month! Caregivers are the unsung support for millions of people in the United States. The statistics on the number of caregivers is startling and will only increase with the aging population.

It is also a time when we can have crucial conversations at dinner with family and friends -- and we are not talking about politics, but the health and well being of family and friends.

I know one of the crucial conversations my family will be having will be on opioids. My youngest of four sons will be playing in his annual tag football game on Thanksgiving morning - a tradition he and his high school friends have kept for 13 years. However, one player will not be taking the field. As a high school star athlete he had an injury that required surgery; developed a life threatening surgical site infection and remained in ICU in the hospital for several weeks; followed by additional surgeries at another hospital. As his body was ravaged by his health journey, he had to undertake months of physical rehab where he was given opioids to ease his pain. Unfortunately, he could not shake his addiction to opioids despite help from family, friends, and behavioral health specialists. He died this month from an overdose and leaves behind many that just cannot understand how all this happened - and how it continues to happen. He was in the age group that is experiencing the highest death rates from opioids. Included in this newsletter are some articles and recent call to actions to address adolescent and young adult opioid addictions.

In this newsletter, you will find information on:

- Caregivers
- Crucial Conversations on Opioids
- Federal Developments - Cost of Care Hospital Transparency; Direct Primary Care Contracting; Beneficiary Engagement and Care Coordination Toolkit
- Call for Patients, Families, and Caregivers for CMS Technical Expert Panels
- PPC at Conferences and Giving Back

Caregivers

According to the National Family Caregiver Alliance, there are approximately 43.5 million caregivers that have provided unpaid care to an adult or child in the last 12 months and of the 43.5 million, 34.2 million Americans have provided unpaid care to an adult age 50 or older in the last 12 months. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.].

According to the [National Family Caregiver Alliance](#), “a caregiver—sometimes called an informal caregiver—is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living or medical tasks. The value of services provided by informal (unpaid) caregivers has steadily increased over the last decade, with an estimated economic value of \$470 billion in 2013, up from \$450 billion in 2009 and \$375 billion in 2007. [AARP Public Policy Institute. (2015). Valuing the Invaluable: 2015 Update.]” As the baby boomers age, the demand for unpaid caregiver services will only increase.

Often times, you will hear that caregivers feel isolated and sometimes carry a heavy burden. There are organizations locally and nationally that can provide emotional support and may be able to refer the caregiver to services and providers that can assist them. Some of the caregiver support organizations include:

- [AARP](#) - Provides a wide spectrum of guidance on caregiver basics, medical, legal, financial, caregiver life balance, local resources, and more!
- National Alliance for Caregiving released a report on November 26, highlighting the challenges of an estimated 11 million Americans that are caring for an adult while also caring for children at home. The report entitled, [“Burning the Candle at Both Ends: Sandwich Generation Caregiving in the U.S.”](#) provides quantitative and qualitative information and stories on the challenges the Sandwich Generation is experiencing.
- [Family Caregiver Alliance](#) - Provides education, advocacy, and policy information on caregivers
- [National Coalition on Aging \(NOA\)](#) - In recognition of Caregivers Month and Alzheimer’s Awareness Month – the National Coalition on Aging released a webinar series publicly available on National Coalition on Mental Health and Aging Webinar Series- [The Invisible Health Care Provider: Family Caregivers of Individuals with Dementia](#) NOA also provides services and support for caregivers.
- [Administration for Community Living](#) - Federal program that provides linkage and support for initiatives to support caregivers.
- Local and state programs also exist that can provide guidance and assistance to caregivers

Kaiser Health News’ *Navigating Aging* with Judith Graham, a contributing columnist, who has written for The New York Times, Chicago Tribune, Stat, The Washington Post and the Journal of the American Medical Association, and other organizations. In addition to this website feature, Judith also has a Facebook page where there are dozens of entries and commentaries from people every day.

Recently, Judith Graham moderated a live panel discussion of leading experts and caregivers on November 20 on “Intimate Lessons From The Front Lines Of Family Caregiving.” The discussion is insightful and emotionally challenging as the participants provide personal perspectives on caregiving. The recording is available by clicking [Here](#)

While we recognize the valuable contributions that caregivers make, we should also be discussing how we as a community can further support them and include their voice in all discussions about person and family engagement and patient centered care.

Crucial Conversations on Opioids

Taking time to discuss the usage of opioids with teens and young adults can be a life saving, crucial conversation. In 2017, there were 70,237 drug overdose deaths of which opioids

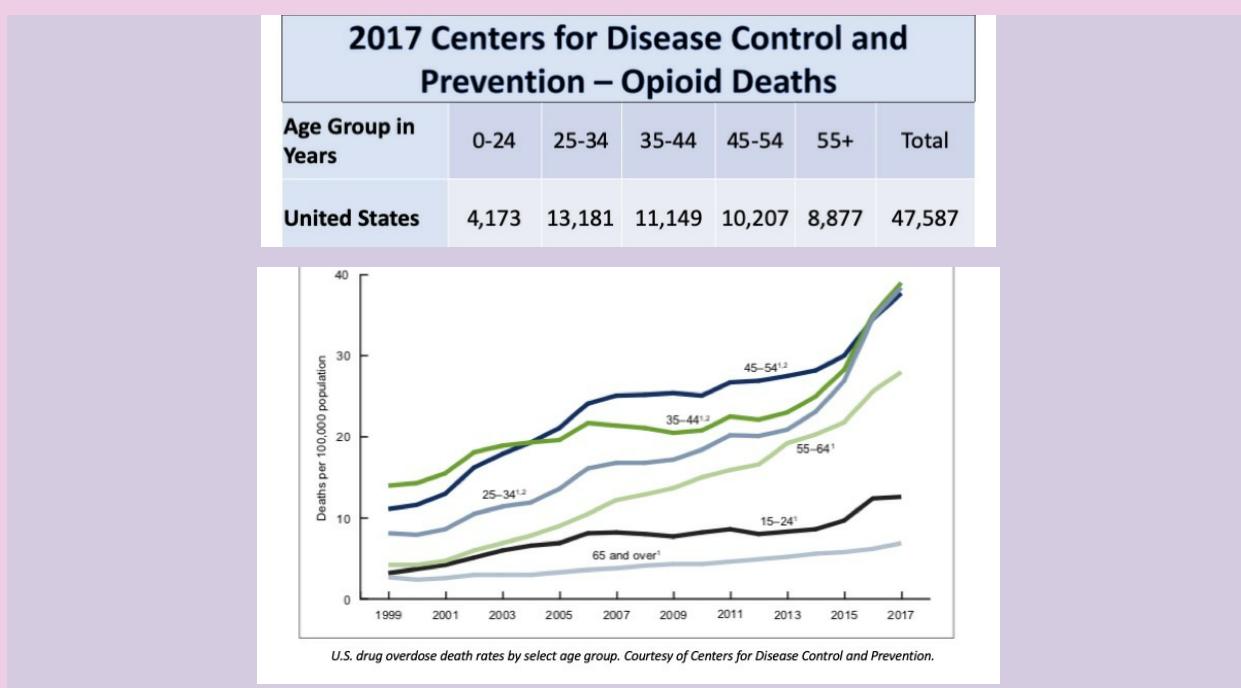
made up 67.8% of the drug overdoses deaths. Many of the deaths due to opioids were among persons that had used opioids for several years.

Several months ago, researchers published a study in the Pediatrics Journal using National Hospital Ambulatory Medical Care Survey and National Ambulatory Medical Care Survey data from 2005 to 2015. (Joel D. Hudgins, John J. Porter, Michael C. Monuteaux and Florence T. Bourgeois Pediatrics June 2019, 143 (6) e20181578; DOI: <https://doi.org/10.1542/peds.2018-1578>). Their findings were of surprise to many as with nearly 57 million visits by adolescents and young adults; the rate of opioid prescribing was 14.9% for Emergency Department visits and 2.8% for outpatient clinic visits. Among Emergency department visits, opioid-prescribing rates were highest among adolescents and young adults with dental disorders (59.7% and 57.9%, respectively), followed by adolescents with clavicle (47.0%) and ankle fractures (38.1%).

According to the [HHS Office of Population Affairs](#), "in 2016, 3.6 percent of adolescents ages 12-17 reported misusing opioids over the past year. This percentage is twice as high among older adolescents and young adults ages 18-25.² The vast majority of this misuse is due to prescription opioids, not heroin. Fortunately, opioid misuse is decreasing. For example, among high school seniors, past-year misuse of pain medication, excluding heroin, decreased from a peak of 9.5 in 2004 to 3.4 percent in 2018."

The usage of opioids at an adolescent age, increases the risk of future opioid misuse. According to another recent study, "Legitimate opioid use before high school graduation is independently associated with a 33% increase in the risk of future opioid misuse after high school. This association is concentrated among individuals who have little to no history of drug use and, as well, strong disapproval of illegal drug use at baseline." Miech, R., Johnston, L., O'Malley, P.M., et al. Prescription opioids in adolescence and future opioid misuse. *Pediatrics* 136(5):1169-1177, 2015. [\[Pubmed\]](#)

These studies suggest that early usage of opioids for a medical reason can provide a pathway to future misuse of opioid drugs in some patients. The 25-34 age group has the highest number of opioid deaths followed by the 35-44 age group.



Health Affairs Blog had an interesting and insightful 'Call to Action' article on the Adolescent and Young Adult (AYA) services and support that should be provided to prevent and address opioid addiction. As the AYAs are sandwiched between children and adult services, they often do not get the screening or supportive services to address opioid usage or addiction. The November 21, 2019 Blog on AYA and Opioids is available by clicking [here](#) with several healthcare leaders contributing to the story ("The Opioid Epidemic: A Needed Focus On Adolescents And Young Adults," Health Affairs Blog, November 21, 2019.DOI: 10.1377/hblog20191115.977344)

Federal Developments - Cost of Care Hospital Price Transparency and Expansion of Value Based Payments

[Cost of Care Hospital Price Transparency](#) - On November 15, CMS released final rules on hospital price transparency to be effective January 1, 2021. The rules require hospitals to

adopt a new standard for price that will include gross, discounted, negotiated payment, and de-identified minimum and maximum negotiated charges with all payers.

Hospitals will be required to display in a consumer friendly format 70 'shoppable services' and 230 services of their own choosing for a total of 300 services. The information must be readily accessible and include all the requirements for display including narrative on the information provided and dates of annual updated information.

Hospitals must also share publicly price information on all of their services in a machine readable format with discounted price arrangements. The information must be updated at least annually and have an accompanying description for each item or service.

Direct Contracting - CMS announced on November 25, the newest models for advancing value based payments - [Direct Contracting Professional and Global](#) through the Center for Medicare and Medicaid Innovation (CMMI). A wide range of primary care organizations can volunteer to accept full or partial risk for managing the care of beneficiaries of traditional Medicare. The goal is to maintain or increase quality with participating providers while reducing overall costs to Medicare and the provider organizations.

Beneficiary Engagement Tools in ACOs - On November 24, CMS announced the release of a new toolkit highlighting strategies used by accountable care organizations (ACOs) and end-stage renal disease (ESRD) seamless care organizations (ESCOs) to engage beneficiaries. Specifically, the [Care Coordination Toolkit](#) explores how ACOs and ESCOs:

- Engage beneficiaries in ACO governance,
- Elicit beneficiary and family feedback,
- Support beneficiaries in self-care management,
- Enhance beneficiary communication in the clinical setting, and
- Communicate with beneficiaries about the ACO as a value-based care organization.

CMS Technical Expert Panels In Need of Patients Deadlines Approaching

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 Panel. CMS has several Technical Expert Panels (TEPs) they are recruiting for and are interested in having patient, family, or caregiver participants on the TEPs. Please note these TEPs have specific patient, family, caregiver needs.

The TEPs and the self-nomination deadlines are listed below:

- Physician Cost Measures and Patient Relationship Codes (PCMP) - Deadline December 20, 2019 - Seeking patients enrolled in Medicare
- Maternal Morbidity electronic clinical quality measure (eCQM) - Deadline December 20, 2019 - Seeking patient with maternal morbidity
- Patient Safety Measure Development and Maintenance - Deadline December 6, 2019 - Seeking patients with experience in hospital quality and safety issues

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

Updated Project Patient Care Web Site and New Podcast

You will now see a new Project Patient Care web site while we are working on the resource web site page. Web site address will remain the same www.projectpatientcare.org

Our Champion Change Agents - TehRay 'Phenom' Hale, Sr. and Marcus Robinson, Ph.D. Phenom and Marcus are having a positive impact on youth and young adults as they spread peacebuilding initiatives and skills throughout Chicago with a focus on the communities that have experienced the



TEHRAY "PHENOM" HALE, SR.
Emcee Skool, LXR.I.C., POETREE



MARCUS ROBINSON, Ph.D.
Collaboration

Champion Change Agents
July 2019

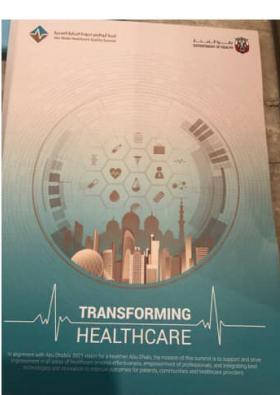
highest incidence of violence now and in the past.

Project Patient Care in Action

Chicago Stand Down Day for Veterans That Are Homeless

Over 700 veterans that are homeless were assisted at Chicago Stand Down Day in the 'Coat Store' as they selected and tried on a coat. Over 550 new winter coats and 350 gently used coats were collected by volunteers for use by veterans at Stand Down Day, Chicago VA Hospital patients, VA supported homeless shelters, and the Clothes Closets for veterans at Jesse Brown and Hines VA Hospitals. Pat has co-chaired the Coat Store at the Chicago Stand Down Day for the past nine years and works with volunteers, veterans and VA staff.

Laura Allen of PPC assists a veteran selecting a winter coat at the 'Coat Store.'



Project Patient Care has a local, national, and international presence. Pat recently was a keynote speaker at the first Abu Dhabi Quality Summit where she highlighted the value and importance of patient centered care and patient, family, and caregiver engagement. Abu Dhabi has a commitment to engaging patients and families while also being transparent in quality and safety improvements.

Pat joined a group of patient advocates and researchers from around the world at the Society to Improve Diagnosis in Medicine's (SIDM)'Diagnosis Error in Medicine Conference.' Pat also joined with Gordy Schiff, M.D., to congratulate him on the Diagnostic Quality Award for his unending focus on improving diagnostic quality. Pat recently worked with Gordy on a Patient Centered Outcomes Research Institute (PCORI) project with SIDM.



Insightful and deep discussions at Annual National Association of Health Data Organizations (NAHDO) in Little Rock on APCDs and EHRs. Pat moderated a discussion on Value Based Purchasing and APCDs. Also spent time with health information leaders she has worked with for over two decades - Joseph Thompson, MD, of Arkansas; Denise Love of Utah; Barbara Rudolph of Wisconsin; and Jo Porter of New Hampshire. In 2020, Pat will be co-chairing the NAHDO Conference to be co-located with National Academy for State Health Policy.



The National Philoptochos Society Children's Medical Fund Luncheon was held in Chicago with 17 national grant awards to healthcare providers for the health and medical needs of children (many awards to Illinois providers). Over 1,000 attendees heard from Honorable Ekaterina Dimakis, Consul General of Greece and were moved by a powerful personal patient story presented by Father Mark Munoz of a Greek Orthodox Church in Minnesota.



Pat met with Dr. Ayanore from Ghana and Georgia Winson from Mission Outreach to explore collaborative projects and a rural outreach healthcare model in Ghana. Pat also met with representatives from India and the country of Georgia to discuss opportunities to improve health and outcomes.



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