Patient Congress 2018

Policy and Advocacy

Webinar # 3

Tuesday September 18, 2018
Welcome

Donna Guinn
Director of Grassroots Advocacy

Melissa Williams
Manager of Health Care Policy and Advocacy

Nicole Braccio
Director of Policy
Housekeeping Items

• Please mute your line
• Type questions in chat box
• Please complete evaluation in chat box
• Agenda
  • Palliative care and PCHETA
  • Patient Protections
  • Financial Security and the Safety Net
  • Patient Congress Logistics
  • Questions
Why Three Issues?

Palliative Care and PCHETA

Your Story

Patient Protections

Financial Security and Safety Net
Palliative Care and PCHETA

Melissa Williams
Objectives

• Define palliative care
• Explain why person-centered care is pivotal to our mission
• Provide a legislative update and discuss provisions of the Palliative Care and Hospice Education and Training Act (PCHETA)
What is Palliative Care?

• Team-based medical care focused on **quality of life for the patient and family** that provides relief from the pain, symptoms, and stresses of serious illness

• Appropriate at **any age and disease stage**

• Provided **along with curative treatment** as an added layer of support
Palliative care = Better quality care
Palliative Care: The “Miracle Drug” Still Missing in Many Clinical Pathways

Rebecca Kirch, JD; Caitlin Donovan; Alan Balch, PhD—Column Editor

If palliative care were a drug, we would be holding hearings on Capitol Hill right now, demanding to know why everyone does not have access to its benefits. We would be writing think pieces, positing ways to bring down palliative care costs; we would be pushing the Food and Drug Administration for fast-track approval. We would be writing of the ways in which we should be incorporating palliative care into clinical pathways.

Instead, when most patients hear “palliative care,” they either do not know what it is, or they think it means care for the dying. Likewise, clinicians often associate palliative care with the end of life or “what to do when there is nothing left to do.”
What’s the Issue?

• **Gaps persist in** professional, public, and policymaker **understanding** about the **benefits of providing palliative care** as part of disease-directed treatment throughout the illness experience.

• **Access to palliative care is limited** — particularly in community settings.

• **The specialist palliative care workforce is in short supply** to reach all patients and families in need.
Palliative care is team-based medical care for those with serious illness. It improves quality of care by:

- Improving patient experience and satisfaction
- Increasing survival
- Reducing cost

The Palliative Care and Hospice Education and Training Act (PCHETA) is a bipartisan bill that expands access to palliative care. Passing the bill could improve quality of life for millions of Americans.

What does PCHETA do?

1. Establishes palliative care workforce training
2. Launches national palliative care education and awareness campaign
3. Enhances research in palliative care

Support PCHETA (H.R. 1676/S. 693) to help patients live better.

To learn more about PCHETA and palliative care, visit patientqualityoflife.org.
1. Establishes palliative care workforce **training**

- **Grants to Medical Schools** and teaching hospitals for career development awards

- **Workforce Development and Fellowships** for doctors, nurses, and social workers

- **Career Incentive Awards** for nurses, social workers
1. Establishes palliative care workforce **training**

To teach front-line clinicians the basic skills of palliative care and ensure palliative care specialists can provide high quality palliative care for the most complex patients.

**Palliative Care Specialists & Front-Line Clinicians**

- Specialized team consultation/co-management (i.e., high ED use, complex decisions, challenging symptoms, poor adherence, high caregiver stress)
- Basic symptom management, communication and coordination to align with treatment goals and support quality of life
2. Launches national palliative care education and awareness campaign

- Requires Agency for Health Research and Quality to use existing authorities to educate patients, caregivers and providers about the palliative care delivery model
- To inform patients, families and health professionals about benefits of palliative care
- Create and disseminate information about available palliative care services

Source: National Survey of 800 adults age 18+ conducted June 2011 commissioned by CAPC, ACS, ACS CAN
2. Launches national palliative care education and **awareness** campaign

*To increase public and health professional awareness of benefits of palliative care services.*

Q. How knowledgeable, if at all, are you about palliative care?

Source: National Survey of 800 adults age 18+ conducted June 2011 commissioned by CAPC, ACS, ACS CAN
3. Enhance research in palliative care

• Directs National Institutes of Health (NIH) to use existing authorities and funds to develop research strategy in palliative care to addresses quality of care and quality of life for patients with serious illness.

• Expands federal support for research at the NIH
  • Palliative care, symptom management, pain management
3. Enhance **research** in palliative care

*To strengthen clinical practice and build the palliative care evidence base for improved quality care delivery.*

Total federal funding for palliative care research is less than 0.1% of NIH budget

Bill Update: PCHETA

• PCHETA unanimously passed in June by voice vote out of the House, with 285 cosponsors.

• The Senate bill remains bipartisan with 33 cosponsors.

• Awaiting Senate HELP hearing
Main “Ask”

Please cosponsor the Palliative Care and Hospice Education and Training Act, S 693, bipartisan legislation that will expand access to palliative care and improve the quality of life for millions of Americans.

If already a cosponsor, thank you for supporting the Palliative Care and Hospice Education and Training Act!
From Chairman Walden

“I’ve heard about this bill’s impact from palliative care specialists and disease advocates from Oregon, like Dawn Frazier in Bend, Oregon, whose daughter Rhonda tragically passed away at the age of 34 after suffering from early onset Alzheimer’s. I’d like to submit for the record a Bend Bulletin op-ed that Dawn wrote about this bill into the record.”
Preserving Patient Protections

Nicole Braccio
Objectives

• Define patient protections
• Understand how the latest health policy developments affect people
• Explain why patient protections are critically important to preserve
What are Patient Protections?

Set of guardrails and rights that make health coverage affordable, more fair and easy to understand.
What’s the Buzz in 2018?

- New regulations for insurance plans
- Less outreach and help for open enrollment
- Work hours as a condition for keeping Medicaid
- Lawsuits challenging various parts of the ACA
New Regulations for Insurance Plans

What do people need?

Comprehensive coverage, more expensive

Fewer covered benefits
“skinny plans”, cheaper premiums
Open Enrollment 2019

- Outreach and assistance funding has decreased by 84% between 2016 – 2018
- Many navigator programs will discontinue
- Shortened enrollment period (45 days)

How are States reforming their Medicaid programs?

- State waivers would require people to complete and report work hours in order to keep Medicaid coverage.

- The result? As of Sept 9, over 4,300 people on Arkansas Medicaid lost coverage for failing to meet requirements.

- Other waivers could limit certain benefits.

Lawsuits Challenging the ACA and More

**ACA**

- **Texas vs. United States**
  
  Is ACA workable without individual mandate in play?

**Medicaid**

- **Stewart vs. Azar (Kentucky)**
  
  Do work requirements violate Medicaid’s purpose?
We Must Preserve Patient Protections

- Not all people with pre-existing conditions are protected from unfair insurance practices.

- Some in “skinny plans” could be charged more or denied coverage for pre-existing conditions.

Your personal story will reinforce WHY patient protections must be preserved!
Optional “Ask”

Preserve patient protections and coverage standards to ensure all people have equitable access to health care.

- People like me/my family coping with serious or chronic illness should be able to purchase an affordable plan with benefits we need.

- We should not be charged more, denied coverage or benefits based on a pre-existing condition.

- More people than ever before support the importance of making equitable access to affordable, quality health care available for all.
Financial Security and the Safety Net

Melissa Williams
Objectives

• Define safety net
• Explain why protecting financial security and access to safety net are important to NPAF
• Provide update on Medical Debt Relief Act
• What else can you do?
What is the Safety Net?

• Public and private programs that protect low-income individuals and families from the hardships and disparate outcomes of poverty.

  o Medicaid, Children’s Health Insurance Program (CHIP), Supplemental Nutrition Assistance Program (SNAP), Low-Income House Energy Assistance Program, Temporary Assistance for Needy Families, Supplemental Security Income

  o Local churches, food banks, free clinics, Meals on Wheels, NeedyMeds, Patient Advocate Foundation
What’s the Issue?

When Credit Scores Become Casualties Of Health Care

Life-Threatening Heart Attack Leaves Teacher With $108,951 Bill

Even a small amount of medical debt can trigger headaches

Even the Insured Often Can't Afford Their Medical Bills

The debate over the future of healthcare is obscuring a more pedestrian reality: Insurance may handle most costs, but many Americans still need to turn to charity for help when they get sick.
What’s the Issue?

Trump Signs Order to Require Recipients of Federal Aid Programs to Work

Crippling Medicaid Cuts Could Upend Rural Health Services

‘We would literally not survive’: How Trump’s plans for the social safety net would affect America’s poorest

Food for Thought

Trump Administration Wants To Decide What Food SNAP Recipients Will Get

February 12, 2018 - 3:21 PM ET

The Upshot

Hate Paperwork? Medicaid Recipients Will Be Drowning in It

Kentucky’s new Medicaid waiver will ask low-income people to jump over hurdles to keep their coverage. Evidence suggests that many will fail.

Behind Trump’s plan to target the federal safety net
What’s the Issue?

• **Rising costs of health care** and resulting **medical debt** suggest demand for safety services and supports will only increase.

• There are **threats to public programs** and **charities cannot keep up** with the demand.

• This leaves **low-income patients and families, seriously ill people at risk of financial and household material hardships.**
Faces of the Safety Net

- Low-income adults and their families
- Children with special needs
- Pregnant women
- People with disabilities
- The elderly
Bill Update: Medical Debt Relief Act

- S. 3351 reintroduced early August
- Champion: Sen. Jeff Merkley (D-OR)
- No new medical debt can be included in credit reports until 180 days have passed
- Information related to a fully paid or settled medical debt will be removed from a credit report within 45 days of the debt being fully settled
Optional “Ask”

Protect the financial security and access to safety net services for patients, families and caregivers facing serious illness.

• Health care costs are the top health care issue for voters.

• Debt crises is the second largest issue affecting patients and caregivers contacting Patient Advocate Foundation

• Public and private safety net programs, like Patient Advocate Foundation, provide an extra layer of support and security for patients and families facing financial or household material hardships.
Bringing it all together

**Patient Congress 2018**
*Amplifying the Patient Voice*

**KEY MESSAGES and FACTS**

**ABOUT NPAF**

NPAF’s mission is to bring patient and caregiver voices to health system delivery reform.

We develop and drive initiatives promoting equitable access to affordable quality health care through policy action and public and private partnerships.

**THE PALLIATIVE CARE AND HOSPICE EDUCATION AND TRAINING ACT WILL**

1. **Establish palliative care workforce training** to teach frontline clinicians the basic skills of palliative care and ensure palliative care specialists can provide high quality palliative care for the most complex populations of the seriously ill.

2. **Launch a national palliative care education campaign** to increase public and health professional awareness of benefits of palliative services.

3. **Enhance research in palliative care** to strengthen clinical practice and person-centered quality healthcare delivery.

**MAIN ASK**

Please cosponsor the Palliative Care and Hospice Education and Training Act, S 693, bipartisan legislation that will expand access to palliative care and improve the quality of life for millions of Americans.

**WHY WE MUST PROTECT EQUITABLE ACCESS TO CARE**

- People coping with serious or chronic illness should be able to purchase an affordable plan with benefits we need
- We should not be charged more, denied coverage or benefits based on a pre-existing condition.
- More people than ever before support the importance of making access to quality health care equitable and affordable for all.

**OPTIONAL ASK**

Preserve patient protections and coverage standards to ensure all people have equitable access to affordable, high quality health care.

**WHY SAFETY NET SERVICES AND SUPPORTS ARE IMPORTANT TO PROTECTING THE FINANCIAL SECURITY OF PATIENTS AND FAMILIES:**

- Health care costs are the top health care issue for voters.
- Debt crises is the second largest issue affecting patients and caregivers contacting Patient Advocate Foundation.
- Public and private safety net programs, like Patient Advocate Foundation, provide an extra layer of support and security for patients and families facing financial or household material hardships.

**OPTIONAL ASK**

Protect the financial security and access to safety net services for patients, families and caregivers facing serious or chronic illness.
What will you leave behind?
Reminder

Please opt-in (or out) of the Story Slam at:

www.npaf.org/patient-congress/patient-congress-2018
Patient Congress Logistics

• You will receive an email on Thursday
• Location: Hyatt House at 725 Wharf Street SW
• Agenda on website
• Registration at 11:00 am on Wednesday
• Dress code
• Weather
• Transportation
Questions?
Policy Issues, Logistics
Contact Info

Donna Guinn
Director of Grassroots Advocacy
703-489-2727
donnag.Kaufman@npaf.org

Melissa Williams
Manager of Health Care Policy and Advocacy
melissa.Williams@npaf.org

Nicole Braccio
Director of Policy
nicole.braccio@npaf.org