Addressing the Burdens Associated with Serious Illness:
Policy Solutions for Patients and Caregivers

The 11th Annual National Conference of Caregiver Advocates
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Our Mission

To bring patient voices to health system delivery reform by promoting equitable access to affordable, quality healthcare through advocacy action and public and private partnerships.
Patient Advocate Foundation

501(c)(3) national non-profit which provides professional case management services to Americans with chronic, life threatening, and debilitating illnesses.

Seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment, and preservation of their financial stability.
**NPAF Policy Priorities**

- **EQUITABLE ACCESS**
  - “Repeal and Replace” Activity
  - Affordable Care Act
  - Medicaid Eligibility
  - Coverage Issues: Benefit Design and Utilization Management

- **AFFORDABILITY**
  - Medical Debt and Balance Billing Protections
  - Cost of Living Burdens
  - Limiting Out-of-Pocket Costs

- **QUALITY HEALTHCARE**
  - Value-Based Care Delivery
  - Palliative Care and Quality of Life
Is Family Caregiving the Next Public Health Crisis?
Social, Psychological and Financial Burden on Caregivers of Children with Chronic Illness: A Cross-sectional Study.
Khanna AK¹, Prabhakaran A², Patel P², Ganjiwale JD³, Nimbalkar SM⁴,⁵.

Caregivers of patients with amyotrophic lateral sclerosis: investigating quality of life, caregiver burden, service engagement, and patient survival.
Burke T¹,², Galvin M³, Pinto-Grau M³,⁴, Lonergan K³,⁴, Madden C³, Mays J³, Carney S³,⁴, Hardiman O³,⁵, Pender N³,⁴.

A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities
Jennifer L. Wolff, PhD; Brenda C. Spillman, PhD; Vicki A. Freedman, PhD; Judith D. Kasper, PhD

Roles of Changing Physical Function and Caregiver Burden on Quality of Life in Stroke
A Longitudinal Dyadic Analysis
Gianluca Pucciarelli, Ercole Vellone, Serenella Savini, Silvio Simeone, Davide Ausili, Rosaria Alvaro, Christopher S. Lee, Karen S. Lyons
# Patient and Caregiver Burdens

<table>
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<th>Caregivers</th>
<th>Patients</th>
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## NPAF Policy Priorities

### Equitable Access
- “Repeal and Replace” Activity
- Affordable Care Act
- Medicaid Eligibility
- Coverae Issues: Benefit Design and Utilization Management

### Affordability
- Medical Debt and Balance Billing Protections
- Cost of Living Burdens
- Limiting Out-of-Pocket Costs

### Quality Healthcare
- Value-Based Care Delivery
- Palliative Care and Quality of Life
Medical Debt Protections

The Issue

• 1 in 4 Americans affected by medical debt, and accounts for more than half of all bankruptcies

• Affects all populations regardless of age, insurance status, or ethnicity

• Is not predictive of a patient’s future credit worthiness

• Can result in the loss of employment or home for many patients

• Can impact a patient’s credit score for years long after the debt has been settled
Advocacy Actions

Federal

- Medical Debt Relief Act
- Comprehensive Consumer Credit Reporting Act of 2016

State

- Out-of-network bills / Surprise medical bills
Cost of Living Burdens: Transportation

The Issue

- A lack of transportation to health care providers constitutes one of the most significant barriers to care for many patients in both urban and rural settings.

- Research shows that the lack of access to affordable transportation disproportionately affects lower-income, elderly, women and minority populations.

- In a survey of low-income adults, 25 percent of missed appointments were due to transportation issues.

- In a PAF survey, 60 percent of patients were dependent on a family member, caregiver, or friend as a means of transportation.
Advocacy Actions

- BRIDGE Coalition - a cross-sector and cross-industry group of stakeholders with the goal of connecting the worlds of healthcare and transportation

- Supporting community programs, i.e. Rides to Wellness
Improving Quality of Life

The Issue

- **Gaps persist in** professional, public, and policymaker **understanding** about the definitions, availability, and value of integrating **palliative care** and other support services.

- Community-based palliative care remains very **limited** or **unavailable**.

- The **specialist palliative care workforce is inadequate** to reach all patients and families in need across the entire disease trajectory.
Advocacy Actions

*Federal*

- Patient Quality of Life Coalition
- Palliative Care Hospice Education and Training Act (PCHETA)

*State*

- Palliative care model legislation
# Patient and Caregiver Burdens

## Caregivers
- Emotional stress
- Financial strain
- Job retention

## Patients
- Emotional stress
- Financial strain
- Job retention

- Decreased quality of life / inability to complete activities of daily living
Addressing the Burdens for Patients and Caregivers

Work together to raise awareness

Develop policies that lead to innovative solutions

Patients, families, and caregivers must be a part of the multi-disciplinary care team, health care decisions, and intervention strategies

Put patients and families at the heart of health delivery reform by advancing person-centered care

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THANK YOU