The NYS Palliative Care Collaborative
Taking Action to Assure Access to Care
Empowering people to assure access to care

FOUNDING PARTNERS

Hospice & Palliative Care Association of New York State (HPCANYS)

American Cancer Society Cancer Action Network (ACS CAN)
Introduction of Founding Leaders
Mission of both organizations & Organizational leaders

HPCANYS
Mission Statement:
To promote the availability and accessibility of quality hospice and palliative care for all persons in New York State confronted with life-limiting illness.

ACS CAN
Mission Statement
The American Cancer Society and ACS CAN are independent organizations that share the same goal: to save lives and to diminish suffering from cancer. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority.

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Kathy McMahon has served as the President & CEO of the Hospice and Palliative Care Association of New York State for thirteen years. She is involved in all educational activities undertaken by the Association and has advocated for statute and regulation to create greater access to pediatric palliative care for over ten years. Ms. McMahon serves on numerous committees including the HPCANYS Children’s Hospice and Palliative Care Advisory Group.

Joan Dacher, PhD., MS, BS, RN, GNP, currently serves as a Professor of Nursing and Director of the Nursing Science Program at The Sage Colleges. Joan has worked in the field of Gerontology and End of Life care for 27 years. She holds a PhD in Gerontology and Health Policy from the Nelson Rockefeller College of Public Affairs and Policy as well as a post-doctoral certificate from Harvard Medical School in Palliative Care Education and Practice. Joan previously served as the Director of the Palliative Home Care Program at The Community Hospice. Joan serves on the Board of Trustees of HPCANYS is the Chair of HPCANYS Palliative Care Advisory Committee.
**Introduction of Founding Leaders**
**Mission of both organizations & Organizational leaders**

**Michael Burgess,** currently serves as the New York Government Relations Director for the American Cancer Society Cancer Action Network, Inc. Mike has 37 years of experience as an advocate for seniors, human needs and has been a change agent involved in many significant public policy activities in New York State government including creation of EPIC program. Mike served with Governors Spitzer and Paterson overseeing the New York State Office of the Aging (NYSOFA) the Senior Action Network. He also Chaired the New York State Family Caregiver Council and co-chaired EPIC Panel.

**Theresa Tolokonsky,** leads the ACS CAN New York State Grassroots Management Team and came to the organization in 2013. Prior to that, she worked in the New York State Assembly as the Legislative Director for Assemblywoman Ellen Jaffee, where she was successful in passage of breast density inform legislation. Theresa began her career as a grassroots organizer for the New York Public Interest Research Group and later the Sierra Club, with a keen interest in mobilizing communities for progressive and sound public policy change.
Statement of **objectives** for the webinar

• Convening an engaged collaborative where entities take on active roles.
• Introduce the mission, and platform of the collaborative to new and potential members
• Discuss working definition of palliative care and how it is operationalized in NYS
• Define activities: how collaborative partners can engage their constituents and organizations in their community
Who was invited and who is engaged?

• (51) **Advocacy Groups** within:
  - Disease specific advocacy organizations, i.e., Alzheimer Association, ALS
  - Educational Institutions
  - Hospitals and health care providers
  - Faith based organizations
  - Consumer Rights Groups
  - Professional Associations

• 14 organizations across the state have formally joined the collaborative
It was clear that in an audience of individuals knowledgeable about cancer there was a clear deficit concerning palliative care...lots of questions were raised.

Goals for cancer care and treatment are congruent with those for palliative care in that they are holistic, community focused and oriented towards a wellness perspective.

Leaders from HPCANYS and American Cancer Society Cancer Action Network (ASC AN) engaged in conversation and recognized the need and the mutual desire to move forward with taking action on assuring PC is more readily available.

Origins of the Palliative Care Collaborative:
Plenary presentation at the 2013 NYS Department of Health Cancer Prevention and Control Meeting:
“Making a Difference Across Communities: Putting the State Plan into Action”
Knowledge deficits revealed during the conference demonstrated a need for a sophisticated response that will address all levels of need.

- What is palliative care?
- How is it different from hospice?
- How is it paid for?
- Who are the providers?
- How are providers prepared to work in palliative care?
- How can Palliative Care be incorporated in the continuum of comprehensive care for individuals with cancer?
The NYS Palliative Care Collaborative is a **Response** to these knowledge deficits

**Mission:** To foster individual, family and community support for education about and access to quality palliative care for all New Yorkers upon diagnosis of a chronic, progressive or life-limiting illness.

**Vision:** Growing a grassroots network for education and action
The NYS Palliative Care Collaborative is a **Response** to these knowledge deficits

- Palliative Care is one of the priorities for advocacy action at the national level and in each state by the American Cancer Society Cancer Action Network (ACS CAN) because pain management and coordinated care are essential for improving the quality of life for patients with serious or life-limiting illnesses.

- Patients, families and caregivers can be a powerful force in articulating the importance that medical care must to be coordinated with emotional, spiritual and social support; health providers and faith communities will also play key roles in advocacy.
The NYS Palliative Care Collaborative is a **Response** to these knowledge deficits

- Desire to create a grass roots base for action and prepare a toolkit showing how a community can develop a palliative care education and advocacy campaign
- Fact sheets, sample letters, and patient profiles will be developed and used in contact with legislators
NYS Palliative Care Collaborative Platform
(What are we doing?)

• Identify and bring together otherwise separate communities of interest for whom access to Palliative Care is or would be a highly valued model of care.

• Support a grassroots movement that will give voice to the existing need for Palliative Care among individuals, families and the healthcare provider community.

• Identify individuals with the potential to become community-based activists and leaders on behalf of Palliative Care.
NYS Palliative Care Collaborative Platform
(What are we doing)

• Influence legislation and policy for Palliative Care by developing a clear policy agenda promoted through the strength of a collective voice.

• Facilitate a clear understanding of Palliative Care’s essential role from the point of diagnosis up to and including hospice care.

• Develop and implement public education strategies regarding the rights to palliative care as mandated in the NYS Palliative Care Information Act (PCIA) & Palliative Care Access Act (PCAA).

• Create a foundation for sustainable partnerships for ongoing Palliative Care Education.
Do we all know what **quality palliative care** looks like and what it is?

**Definition:** *Palliative Care is patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative Care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.*

Death & Bereavement

Modifying Therapy, Curative, restorative intent

Life Closure

Risk

Disease

Condition

Palliative and Hospice Care

Palliative and Hospice Care

Death & Bereavement
Do we all know what **quality palliative care** looks like and what it is?

Quality indicators and outcomes (NQF)

- Enhanced and integrated inter-professional care for chronic and advanced illness

- Patient centered and patient driven care based on the values, preferences and goals of the individual
Do we all know what quality palliative care looks like and what it is?

Quality indicators and outcomes (NQF)

• Comprehensive needs of the patient and significant others are identified early on and better met during the course of care

• Optimal support for management of physical, psych-social and spiritual needs

• Ethical, legal and regulatory aspects of health care decision making are taken into consideration
Factors that limit the availability of Palliative Care

- Reimbursement streams
- Workforce capacity
- Lack of community knowledge of palliative care and benefits, not knowing what to ask for
- Fear of the end of life and death
- Lack of public conversation about chronic illness and end of life. This remains a taboo subject
- Confusion about PC vs EOL care
Why create a broadly based collaborative rather than focus on a specific diagnosis?

• Needs cut across all populations
  ◦ Chronic, life limiting illness at the time of diagnosis regardless of prognosis, age

• Power exists in bringing together representatives across multiple realms and entities
  ◦ Strength exists in numbers and partnerships, collaborations

• Opportunity to learn from one another. re: outreach, educational opportunities, methods

• Broader issues concern everyone
Palliative care is a paradigm shift with potential to impact many groups

• Palliative Care lives in the space between treatment, striving for a cure, and end of life care. Palliative Care must be a component of care with anyone diagnosed with illness requiring long term management.

• Palliative care is not well understood for what it is. Rather it is often defined for what it is not.
Palliative Care Collaborative, an Agent of Advocacy

Advocacy Agenda:

• Legislative Advocacy – seek new funding for the palliative care training for health care professionals

• Advocacy with health care systems with local interaction with providers to discuss their programs and services and what changes they are making to integrate palliative care into quality of life care

• Encourage local collaborative members to conduct forums in the community to discuss issues and legislative advocacy

• Working with families, caregivers and patient organizations to educate them about how to seek patient-centered care that addresses physical, social, spiritual and emotional needs
Where is advocacy needed and what opportunities are identified
Specific examples of potential for action
7 Points of Action

1. Letters to the editor
2. Meetings with legislators
3. Ongoing communication with legislators
4. Build and maintain relationships with media
5. Your sphere of influence
6. Personal story and testimonials
7. Community champion recruitment
Specific Examples of Potential for Action

Letters to the Editor

• Pertinent to current events (budget, disease prevention, health reform, pain and palliative care)

• Address unmet needs of community

• Rely on key messages to maintain consistency

• Typically 150-200 words
Specific Examples of Potential for Action
Meeting with Elected Officials

• Call ahead for appointment

• Every office has different scheduling procedure

• Plan for 15-20 minutes

• Staff level meetings are extremely helpful

• Jan-June, members are in typically in Albany, Monday-Wednesday
Specific Examples of Potential for Action
Communicating with Elected Officials and staff year round

• Regular communication (info about your program, newsletters, drop-by office)
• Invite to programs, or co-host events (make sure you can accommodate them)
• Honor champions at awards events
• Send copy of all local press clips w/ letter
• Forward your relevant research/surveys
• Testify at hearings and public forums
Specific Examples of Potential for Action

Media Advocacy

- Letters to the editor, op-eds
- Featured personal stories
- Invite press to your events
- Stick to key messages
- Offer personal stories
Specific Examples of Potential for Action

**Sphere of Influence**

• Key contacts/community ambassador

• Who has access to your decision-makers?

• How can they help you send your message?
Specific Examples of Potential for Action

Community Champions:
Engage your Provider/Community Networks

• Who are your stakeholders?

• These local voices can have a big impact on decision-makers

• Deepen connections to the program you are talking about
Specific Examples of Potential for Action

**Personal Story Collection**

• Cornerstone of local sustainability work

• Individuals often can communicate the value of the program best

• Very powerful advocacy tool with legislators

• Crucial to getting media coverage

• Ask your ACS partner to catalog the story and help coach the client to advocate on behalf of the program
The **Collaborative is an opportunity** to share information, resources, partnerships and best practices

- We can reach out to a larger citizen audience through efforts of all the organizations. Sometimes the risk is not recognizing what you do not know and this is likely the case for most individuals who would benefit from palliative care. They do not even know to ask for it.

- Work with and on behalf of the most vulnerable populations to support them in having a voice
Legislative Imperative for Palliative Care in NYS

New York State Palliative Care Statutes:

• Palliative Care Education and Training Act (2007)
• Palliative Care Information Act (PCIA) (2010)
• Palliative Care Access Act (PCAA) (2011)
• Hospice Modernization Act (2011)
Specific examples for Potential Action
What HPCANYS has taken on and the opportunities to continue

Delivery System Reform Incentive Payment (DSRIP)

• Part of MRT Waiver Amendment (CMS approval has been received)

• DSRIP is part of a three-part approach: DSRIP + State Plan Amendment and Managed Care Contract Payments

• End game = a whole new integrated health care system
Specific examples for Potential Action
What HPCANYS has taken on and the opportunities to continue

DSRIP: Local Partnerships

Multiple partners join together to:

- ID community health needs, challenges & quality objectives
- Develop programs & investments w/ measurable metrics and milestones
- Transform the healthcare delivery system by working together
Moving forward: Create our action plan

• Media release and messaging to announce our platform

• Community advocacy day

• Moving forward....
**Activities** participants can take an *active role* in ...

• Reach out to other organizations they are connected to, talk with them about this initiative

• Poll members of own organization to assess what their needs and concerns are re: Education?

• More obvious things like letters to the editors of local newspapers, letters to legislators, letters to insurance providers

• Take action to make this a topic of discussion in senior centers, religious organizations, libraries, etc.
Action to Take Now
‘Story Bank’

• Identifying and **communicating real life stories** of individuals who have benefitted from palliative care and can relate how it improved their care or that of a loved one

• Work with your constituents to **develop case studies** that demonstrate the benefit of palliative care from a personal, family story perspective.

• **Invite members of your organization to share stories** concerning the challenges of managing chronic illness with care as it is usually offered, for use for legislative action and possible newspaper article or op-ed
Action to Take Now ‘Story Bank’

• Stories must be **HIPAA compliant**.

• **Template** will be provided. Elements include:
  - ✓ Organization name / City
  - ✓ Picture of story teller, family or individual receiving care *(optional)*
  - ✓ Background *(what was the situation before PC services were introduced)*
  - ✓ Palliative Care Intervention *(what services were provided for individual, family or caregivers)*
  - ✓ Outcome *(what was different/better after PC services were provided)*

• Information could be shared, used in research or included in a book for advocacy

• Please submit to Theresa Tolokonsky at [theresa.tolokonsky@cancer.org](mailto:theresa.tolokonsky@cancer.org) by October 31, 2014.
Questions? Contact Us

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Last question from participants?
Final thoughts?

Thank you…….

“Be the change you wish to see in the universe”

~Gandhi~