

# Mission

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



# Leadership for a Caring Community

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

## Annual Report

## 2011



# Message from the President



Dear Friends and Colleagues,  
2010–2011 was significant for me, as October 2010 marked my 10th anniversary with HPCANYS. It's been a great honor and privilege to serve the community and our members as we strive to make our mission—quality hospice and palliative care accessible to all New Yorkers with a life-limiting illness—a reality.

I'm gratified that the stars appear to be aligned for hospice and palliative care in New York State. We experienced significant victories this year with increased access to palliative care and expansion of hospice included in the Medicaid Redesign Team's (MRT) final recommendations, which were accepted by the Governor and the Legislature. As you examine the following pages, I'm sure you'll agree that we have much to celebrate.

Our dynamic, ever-changing health care system, and the challenges it presents, also brings with it great opportunities. Now more than ever before, we need a hospice and palliative care community that is united and committed to working together. We have exciting endeavors planned for 2011—working with the NYS Department of Health as the MRT hospice and palliative care recommendations are implemented, development of a New York State pediatric palliative care interdisciplinary training program, and establishment of a Futures Committee.

We have made a difference in end-of-life care in New York State, and our dedicated Board of Trustees, committed members, devoted staff, and strong, supportive partners can be proud. HPCANYS will continue to be proactive to assure that all New Yorkers have access to quality hospice and palliative care. I thank all of our supporters for helping us achieve the many successes highlighted in our 2010–2011 Annual Report.

Sincerely,

Kathy A. McMahon  
President and CEO

## Access to Quality End-of-Life Care

**HPCANYS 2010 – 2013 Strategic Blueprint—Access:** Integrate Hospice and palliative care into the decision trees/protocols for the care of chronically ill persons; Promote availability of hospice and palliative care for underserved populations:

**Access to quality end-of-life care is the keystone of HPCANYS' mission. Strides have been made through:**

### *Partnerships and collaborations*

- HPCANYS Children's Advisory Group continues to serve as a resource to the NYS Department of Health as they implement pediatric palliative care services under the Care at Home I & II Waivers, as well as the new Concurrent Care for Children Program under the Federal Affordable Care Act.
- HPCANYS is an active member of the Coalition for Medically Fragile Children, which is working to assure that medically fragile children and their families have access to medically necessary services under the Concurrent Care for Children Program.
- IPRO's final AIM (Assess, Intervene, Measure) Project Report was issued in November 2010. Kathy McMahon and a number of HPCANYS members served on the project's Technical Advisory Panel.
- HPCANYS is taking a leadership role in the new *We Honor Veterans* program, launched by NHPCO and the Veterans Administration in September 2010.
- We continue to collaborate with NYSARC on projects that will increase access to quality hospice and palliative care for individuals with developmental disabilities.
- HPCANYS shared its new Palliative Care Information Act Resource Center with the NYS Palliative Care Education and Training Council to assist the Council as they developed support information for implementation of the new Act.
- Palliative care is a priority issue for the New York State Cancer Consortium. Kathy McMahon serves on the Steering Committee of the Consortium, co-chairs its policy committee and is a member of the palliative care committee. HPCANYS Board Trustee Joan Dacher chairs the Consortium's palliative care committee.

- HPCANYS is an active member of the Gold STAMP Program to reduce pressure ulcers in New York State. The program is a coalition of organizations convened to improve the assessment, management and prevention of pressure ulcers.
- HPCANYS hosted a meeting of upstate Hospice medical directors and Dr. George Costantino, MD, Medical Director of National Government Services (NGS).
- HPCANYS has reached out to other statewide healthcare associations to make our Palliative Care Information Act Resource Center more widely available to New York's physicians and nurse practitioners.
- HPCANYS continues to partner with HOSPAZ, the Hospice Association of Zimbabwe. In May of 2010, we conducted a fundraising event, the profits of which were used to benefit regional hospice collaboration in Zimbabwe. We also sponsored HOSPAZ's Director on an educational exchange visit to New York.

### *Public Policy*

2010–2011 brought some hard won achievements. The Association's advocacy team—Public Policy Steering Committee, Federal Legislative & Regulatory Subcommittee, State Legislative & Regulatory Subcommittee, and Government Relations Consultant Sandra Rivera—can be proud of their many accomplishments:

### **In New York State**

- A number of HPCANYS recommendations to New York's Medicaid Redesign Team were included in the Team's final report, which was accepted by the Governor and the Legislature:
  - MRT # 109 – Increase access to palliative care in hospitals and nursing homes;
  - MRT # 209 – Expand hospice: 1) expand definition of terminal diagnosis from 6 months to 12 months; 2) include hospice in Accountable Care Organizations (ACOs) and medical homes; and 3) expand concurrent hospice and curative care to Medicaid adults. The Association will work closely with the New York State Department of Health (DOH) as the MRT proposals are implemented.
- HPCANYS established a work group and worked closely with the Task Force on Life and the Law to develop amendments to include hospice in the Family Health Care Decisions Act (FHCDA).
- The Palliative Care Information Act was passed and signed into law in August 2010. Through its Palliative Care Advisory Group, HPCANYS developed a web-based Palliative Care Information Act Resource Center to support implementation of the Act.

### **HPCANYS 2010 – 2013 Strategic Blueprint—Public Policy:**

- 1) Position Hospice and palliative care as a critical component of health care reform;
- 2) Assure adequate funding stream for Hospice and palliative care;
- 3) Develop public policy platform to support HPCANYS' mission.

- HPCANYS supported legislation that would improve access to quality hospice and palliative care:
  - Health Care Proxy (A.02186)
  - Pain Management (safe harbor) (A.732)
  - Advance Care Planning (A.4899)
  - Health Care Proxy Information (A.4903)
- We submitted testimony on the Governor's proposed 2011 Medicaid budget and urged restoration of Article 6 Medicaid funding for hospices operated by their county departments of health.
- HPCANYS continues to advocate for making hospice accessible to individuals enrolled in the Long Term Home Health Care (LTHHC) program.

## Federal Legislation & Regulation

- HPCANYS submitted comments on CMS's Proposed Rule for the 2011 Wage Index, underscoring concerns regarding the "double cuts" imposed by BNAF phase-out and productivity factor cuts.
- The Association supports the HELP Hospice Act (S.722) which calls for:
  - A demonstration project to test and evaluate any new hospice reimbursement model;
  - Amendments to the new face-to-face encounter requirement to reflect operational realities for hospice programs; and
  - Increased hospice survey frequency.
- The Association submitted extensive comments to CMS regarding the proposed rule for hospice face-to-face encounters.
- HPCANYS submitted comments to HHS on the Proposed Rule for Modification of HIPAA under the HITECH Act.
- We are working with the New York State Department of Insurance as they look at implementation of health care reform—including the

- essential benefits package and health insurance exchanges—under the Affordable Care Act.
- Implementation of the Concurrent Care for Children provision under the Affordable Care Act is a priority, and the Association continues to work with the NYS Department of Health to assure that Medicaid pediatric patients have access to the medically necessary services for which they are eligible.
- In response to CMS's Request for Information (RFI), HPCANYS submitted comments regarding Accountable Care Organizations (ACOs) and Medicare Shared Savings Programs.
- HPCANYS met with New York's Senators and Congress Members in Washington, D.C. on two separate occasions:
  - February 17, 2011 HPCANYS members traveled to Washington to meet with New York's six newly elected Congress Members. The purpose was to share the value that hospice and palliative care bring to their constituents; and
  - April 6, 2011 we participated in NHPCO's Capital Hill Day and met with the health aides of New York's two Senators and 15 of our Congress Members.
- The Association submitted comments to CMS on their Proposed Rule regarding patient notification of right to access state survey agencies and Quality Improvement Organizations (QIOs).
- We continue to monitor MedPAC's deliberations relative to the Medicare Hospice benefit and will be proactive as changes to the hospice benefit are considered.

## HPCANYS 2010 – 2013 Strategic Blueprint—Education:

- 1) **Improve quality outcomes through education;**
- 2) **Develop educational programs to meet members' needs.**

### 2010 Annual Meeting

2010 marked the 30th Anniversary of HPCANYS' Annual Interdisciplinary Meeting and Seminar, which was held at the Albany Marriott Hotel on May 13-14. *Mission, Vision, Reality... Celebrating 30 Years* was the theme of the conference and the two plenary sessions and 30 individual workshops showcased the myriad ways that New York's hospice and palliative care organizations are maintaining this delicate balance while building upon past success to ensure a vibrant future. Close to 400 individuals representative of the interdisciplinary team and 25 exhibitors from around the country gathered to celebrate this milestone event. To further extend the collaborative reach of this conference, HPCANYS invited Girmelina Matiza, President of the national Hospice Association of Zimbabwe to be our guest and to bring the best of New York State back to her home country.

### Pediatric ELNEC Training

In 2010, New York State began accepting applications from hospices to provide new pediatric palliative care services under the renewed Care at Home I/II waiver program. This expansion increased access to palliative care services for an underserved segment of the population. To meet the training requirement for providers, HPCANYS conducted two pediatric ELNEC educational sessions, certifying 56 individuals to provide care

under the Care at Home program. This two day training was provided in two locations, in Albany and in Manhattan, where it was hosted by Metropolitan Jewish Hospice. Philene Cromwell from CompassionNet in Rochester, NY provided curriculum and training oversight. For 2011, we intend to expand the training even further and, with the help of our Children's Advisory Committee, to develop an original interdisciplinary curriculum that more closely follows the provisions of the Care at Home I/II waiver program for pediatric palliative care services.

### Peer Groups

- **Billers** - HPCANYS hosted a 90-minute audio conference in January 2011 facilitated by Emily Fox-Squairs, Medicare Provider Outreach and Education Consultant, providing an update on National Government Services (NGS) activities, general billing and what's new with Hospice.
- **Finance Officers** - The Finance Officers Peer Group met on October 22, 2010. The featured Guest Speaker was Rich Tinger, RPh, who spoke about controlling pharmacy costs. Structured discussion topics included best practices in reporting for CR 6440, Recovery Audit Contractors, DME providers, billing for palliative care, health care reform and employer obligations and FMAP reductions on Medicaid payments.
- **Palliative Care** - We revitalized the Pediatric Palliative Care Partnership in NYC to facilitate peer group interactions, educational and collaborative opportunities among

providers and team members. HPCANYS will continue to play a supporting role in facilitating networking and educational opportunities for the group that would benefit not only these individual programs but will also help to expand the role of palliative medicine in the health care system.

- **New! Quality/Compliance Officers** - On April 1, 2011, HPCANYS gathered together Quality/Compliance Officers from 22 hospice providers from across the state to meet and discuss the issues of the day. Representatives from IPRO were invited to discuss with the group how the findings of their recently completed AIM project conducted amongst several NYS hospices and palliative care providers may be utilized by CMS.
- **New! Director of Nursing/Director of Clinical Care/Director of Patient Care** - Another new peer group met for the first time on April 15 to share with their colleagues challenges facing them and techniques they have found invaluable. Topics discussed included the Palliative Care Information Act, on-call staffing and the Face to Face Encounter. The networking portion of the meeting allowed participants to follow up with others in the state facing similar issues.

### Fall Leadership Institute

Inspired by the Board of Trustees to create a series of educational opportunities for new and emerging leaders in the field of hospice and palliative care, HPCANYS has undertaken the development of a Leadership Institute designed to

# Public Engagement and Community Outreach

support and encourage leadership in our changing times. The first session, held in April of 2010 was focused on those new to hospice leadership. The second event held November 17, 2010 at the Gideon Putnam Resort and Spa, presented a more in-depth exploration of current challenges. The Fall Leadership Institute featured Gwen Webber McLeod as the Keynote Speaker. Gwen spoke to the audience about the difference between management and leadership and the characteristics of a dynamic leader. She was followed by William Paczkowski, a doctoral candidate in management at the Lally School of Management and Technology, Rensselaer Polytechnic Institute who spoke to the audience about succession planning. The day concluded with a panel presentation on Board Development.

## **Veterans Collaboration**

In September of 2010, HPCANYS collaborated with both VISN 2 and VISN 3 to present two workshops addressing the special needs of veterans at end of life. The VISN 2 event on September 1, 2010 featured Carol Luhrs, MD - "VA's Comprehensive End of Life Care Initiative: Honoring Veterans' Preferences in the VA and the Community" as well as Sheldon Solomon, PhD - "Grave Matters: Caring for Our Veterans." The VISN 3 training on September 28 featured Deborah Grassman, APN presenting "Peace at Last."

## **Pressure Ulcers**

Through our ongoing participation with the GoldSTAMP program to Reduce Pressure Ulcers, a cross organizational collaboration of professional and provider organizations across the health care continuum, HPCANYS and the Center for Hospice and Palliative Care hosted a one day educational program to promote recommended practices and supporting evidence for pressure ulcer improvement and communication within and between care settings. This event was held on January 21, 2011 in Buffalo, NY.

## **HPCANYS 2010 – 2013 Strategic Blueprint—Public Engagement and Community Outreach:**

### **Carry out community outreach to key stakeholders**

- Through the Association's toll-free 800 #, information about hospice and palliative care is available to the public on a 24/7 basis. HPCANYS also distributes printed information, including Family Emergency Planning Guides and makes referrals to appropriate programs.
- HPCANYS provides technical assistance to provider members for a wide array of regulatory issues.
- In November 2010, HPCANYS published an 8-page insert in the November 10, 2010 issue of The Legislative Gazette (Circulation 18,000) targeted for the New York State legislative community.
- During the month of November, National Hospice and Palliative Care month, HPCANYS sponsored several public service announcements (PSAs) on AM radio, blanketing all of upstate New York.
- HPCANYS' Community Outreach Task Force embarked on a web-based platform to provide both hospice and palliative care providers as well as the general public with information about end-of-life services. The Task Force has designed a Community Outreach Tool Kit to assist providers with tips about approaching different audiences with the goal of promoting hospice and palliative care services.
- Through a grant funded by Senator Breslin, Assemblyman Cahill and Assemblyman McEneny, HPCANYS developed web-based video clips providing information about end-of-life care geared specifically to patients and families as they navigate a life-limiting illness. We have made these clips available to all provider members.
- HPCANYS participated in a national effort to promote April 16, 2011 as National Health Care Decisions Day via newsletter articles as well as promoting the event through electronic media.
- HPCANYS continues to promote access to quality hospice and palliative care for individuals with developmental disabilities through its interactive website: [www.ddhospicepalliativecare.org](http://www.ddhospicepalliativecare.org). A quarterly e-newsletter and an on-line discussion forum are available through our website.
- The Hospice Veterans Partnership (HVP) website ([www.hpcanys.org/veterans](http://www.hpcanys.org/veterans)), which provides information to veterans and their families seeking help and services at end of life, has been updated to include advance care planning information, availability of bereavement services and more complete contact information.
- HPCANYS has provided workshops for community-based groups as well as state organizations to promote hospice and palliative care. In November of 2010, Kathy McMahon presented information to the Albany Rotary Club; in June of 2010, Beth Mahar presented a workshop on hospice and palliative care to the New York State Association of Area Agencies on Aging; in May of 2011, Kathy McMahon presented a workshop on hospice in Assisted Living to the Empire State Association of Assisted Living.
- In response to the enactment of the NY State Palliative Care Information Act we created the HPCANYS Palliative Care Information Act (PCIA) Resource Center. Organizing key information and resources under six key topics with corresponding sub-topics, the resource serves as a guide for the treating physician or nurse practitioner. The HPCANYS PCIA Resource Center is also designed to serve as a tool for our provider members to support hospice and palliative care relationships with physicians and nurse practitioners in the communities they serve.
- HPCANYS conducted a pilot needs/strengths assessment with a number of Metropolitan New York hospital-based palliative care providers. The purpose of the assessment was to better understand the barriers, challenges, goals, and needs of these programs, and how the Association can help support them. The final report will help inform new and emerging programs of lessons learned, and best practices as they plan for the future.



# Donors

Thank you to all who so generously supported HPCANYS' mission, programs and services (based on donations made January 1 – December 31, 2010). Every effort is made to ensure our supporters are properly recognized. If your name is not listed, or is spelled incorrectly, please let us know.

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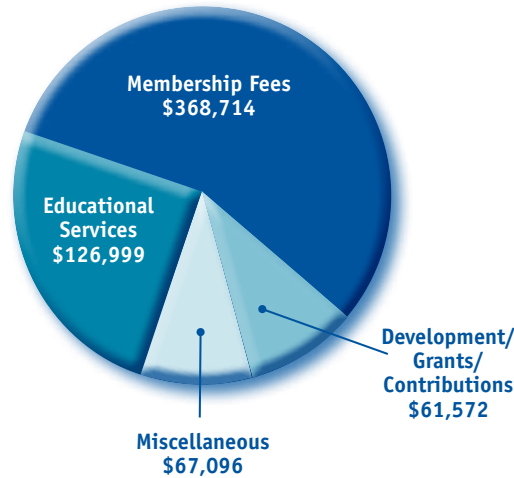
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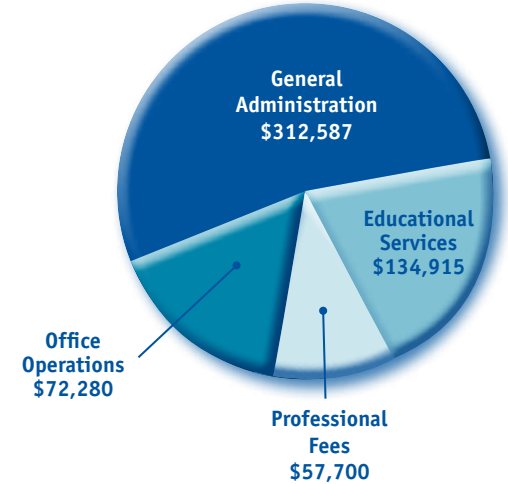
January 1 – December 31, 2010

As is our custom, the financial statement reflects our fiscal year, January 1 – December 31, 2010. These numbers are in draft form, pending completion of the financial statement audit.

2010 Revenue – \$624,381



2010 Expenses – \$580,922



## Membership



## Provider & Allied Membership

