

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.

May 2009 - May 2010



30th Annual report

Dear Friends and Colleagues,



What an honor it is to “ring in” our 30th Annual Celebration! HPCANYS not only celebrates 30 years of accomplishments and success, but also recognizes, and even embraces, the challenges ahead as recently passed health care reform legislation is implemented.

As you peruse this annual report, you’ll see that 2009-2010 was an eventful year, and 2010-2011 promises to be the same. Access to quality hospice and palliative care is our mission and the driving force behind the Association’s Strategic Blueprint, drafted in the fall of 2009 and now being implemented. It’s an ambitious undertaking, with several completed activities reported on these pages, and more to come in next year’s annual report.

Through our dedicated Board of Trustees, committed members, devoted staff, and strong, supportive partners, we have made a difference in end-of-life care in New York State. The number of patients receiving hospice care continues to increase. The most recent data from the NYS Department of Health demonstrates that 43,747 patients received hospice care in 2008, an increase of 2.8%. In 2008 9,551 nursing home residents received hospice services, an increase of 3%.

HPCANYS will continue to be proactive to assure that all New Yorkers have access to quality end-of-life care. I thank all of our supporters for helping us achieve the many successes highlighted on the following pages.

Sincerely,

Kathy A. McMahon
President and CEO

Access to Quality End-of-Life Care

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 served as a resource to the NYS Department of Health as they developed the provider application for pediatric palliative care services, now being implemented as a new service within the Care at Home I & II Waiver.
- The Association’s Quality Task Force offered assistance to NYS DOH as they kicked-off phase one of their Hospice Quality Initiative.
- Kathy McMahon and a number of HPCANYS members serve on the Technical Advisory Panel of the new AIM (Assess, Intervene, Measure) Project, a CMS quality project grant awarded to New York’s IPRO.
- Now in its seventh year, our partnership with the Veterans Administration refocused its attention on reinvigorating the regional HVP partnerships.
- Through our collaboration with the NYS Developmental Disabilities Planning Council and NYSARC, we continue to focus on making quality end-of-life care more accessible to individuals with developmental disabilities.
- The NYS Palliative Care Advisory Council, on which HPCANYS

- President/CEO Kathy McMahon serves, has developed draft RFAs for two grants—1) Palliative Care Physician Educator and Champion Program, and 2) Institute for Palliative Care Faculty Development, which will be released once regulations for palliative care certified medical schools and residency programs are finalized.
- We continue to work with the NYS Long-Term Care Restructuring Initiative through our representation on the NY Connects Long Term Care Advisory Committee.
- NYS Cancer Consortium’s Palliative Care Program Committee is working on revising/updating the Palliative Care Section of the NYS Cancer Control Plan.
- The Association completed its third emergency preparedness contract with the NYS Department of Health to develop and present statewide train-the-trainer sessions to implement palliative care/hospice resources curriculum for health care providers of ventilator-ineligible patients. Contract 4, focusing on: 1) building HPN compliance capabilities and 2) promoting healthcare worker

- compliance regarding seasonal and H1N1 flu vaccine regulatory requirements is currently underway.
- HPCANYS continues to participate in meetings of the NYS Office of Aging’s Family Caregiver Council.
- The Association is an active member of the coalition that developed the Gold STAMP Program to reduce pressure ulcers in New York State.
- HPCANYS participates in the NYS Office for the Aging’s “Thinking Group” to help conceptualize the core design components for a new state initiative to develop a Community Supports Navigator.
- Several activities—a literature search and development of focus groups—designed to help integrate hospice and palliative care into protocols for care of chronically ill persons, are now underway with the support of the Sage Colleges Department of Nursing and University Buffalo School of Social Work.

COMMUNICATION

HPCANYS...

- publishes a quarterly newsletter, *The Reporter*
- e-mails a weekly electronic newsletter, *Hospice News Network*, to provider and allied association members
- issues provider memos on need-to-know issues and topics to hospice and palliative care administrators on a timely basis
- sends *Quality of Life Matters*, a quarterly physician’s newsletter to hospice medical directors
- provides technical assistance to HPCANYS members on a wide range of topics
- offers Hospice market reports as a subscription service to its hospice members through its partnership with Hospice Analytics.

Public Policy

2009-2010 brought some hard won achievements. The Association's advocacy team—Public Policy Steering Committee, Federal Legislative & Regulatory Sub-committee, State Legislative & Regulatory Sub-committee, and Government Relations Consultant Sandra Rivera—can be proud of their many accomplishments.

In New York State...

- After 17 years the Family Health Care Decisions Act (FHDA) was passed by the Assembly and Senate and signed into law. The Association has already begun advocating for amendments to allow surrogate decision making in community-based settings.
- The Association successfully advocated against proposed cuts in the 2009 Medicaid budget to hospices operated by county departments of health.
- We submitted testimony on the Governor's proposed 2010 Medicaid budget, again protesting proposed cuts that would put hospices operated by county departments of health at risk for closure.
- Expanding the definition of terminal prognosis from 6 months to 12 months is a priority goal being explored by HPCANYS.
- The Association seeks to address barriers to access to palliative care presented by the Corporate Practice of Medicine Act.
- Legislation designed to ease site selection for hospice residences was passed in the Assembly and introduced in the Senate (A.1750/S.7194).

- HPCANYS supported legislation that would improve access to quality hospice and palliative care:
 - Pain Management Education (A.5287/S.4387)
 - Pain Management Safe Harbor (A.2263/S.4499)
 - Witness to Health Care Proxy (S.1990/A.3787)
 - Components of the Home Care Accessibility and Efficiency Act (S.5179)
- HPCANYS continues to advocate for making hospice accessible to individuals enrolled in the Long Term Home Health Care (LTHHC) program.
- Support for inclusion of hospice and palliative care in medical home models was presented at Senator Duane's Medical Home Roundtable.
- President/CEO Kathy McMahon presented testimony at the New York State Senate Committee on Aging's Public Hearing on the advance care planning

consultation provision in HR 3200 (America's Affordable Health Choices Act of 2009).

Federal Legislation & Regulation...

- The Final Rule for the 2010 Wage Index lessened the effect of Budget Neutrality Adjustment Factor phase-out by spreading the phase-out over seven years.
- Although productivity factor adjustments to hospice reimbursement, included in health care reform legislation, were somewhat mitigated in the final bill, we continue to seek relief from "double cuts."
- HPCANYS supported a number of provisions in recently passed Health Care Reform legislation:
 - A 15-site concurrent care demonstration model;
 - A concurrent care coverage for children diagnosed with a life-limiting illness;
 - Education and training programs in pain care; and
 - Research and treatment for pain management.

- HPCANYS had two successful "Hill Days," as we took our message to Washington, D.C. in December 2009 and April 2010.
- Comments were submitted to the Center for Medicare and Medicaid Services (CMS) relative to the Proposed Hospice Wage Index for FY 2010, including the Budget Neutrality Adjustment Factor phase-out.
- 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 will be proactive as health care reform is implemented.



EDUCATION

- **2009 Annual Meeting-** "Embracing Change... Transforming the Future" was the theme for the two-day conference, held May 28-29, 2009 at the Saratoga Hilton Hotel and Conference Center in Saratoga Springs, NY. Two plenary speakers, and 29 concurrent workshops offered topics that included symptom management, open access, the latest in palliative care, staff renewal, bereavement, pediatric hospice care, and fundraising. Over 300 hospice, palliative care and allied professionals enjoyed stimulating workshops and peer interaction at the 29th Annual Interdisciplinary Meeting.
- **Pediatric ELNEC Training** - This two day training was provided in two locations, Buffalo and Manhattan. A version for pediatric palliative care nursing education, adapted from the ELNEC curriculum to provide current education and extensive knowledge for nurses related to palliative care for children, this training was hosted by The Center for Hospice & Palliative Care in Buffalo and by VNSNY Hospice Care in New York City. Susan Huff, RN, MSN, from Johns Hopkins Pediatric Home Care Program provided curriculum development and training oversight.
- **Finance Officers Meeting** - In October, HPCANYS brought together Finance Officers from hospice programs across the state to hear the latest changes to fiscal procedure required by the Centers for Medicare and Medicaid. Emily Fox-Squairs,

HPCANYS Strategic Blueprint

Developed in the fall of 2009, the 2010 - 2013 Strategic Blueprint is an ambitious roadmap to support HPCANYS' mission to promote the availability and accessibility of quality hospice and palliative care. Over the next three years, the Association will be working on short-term and long-term strategies focusing on access, public policy and education:

- **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.
- **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.
- **Education**—1) Improve quality outcomes through education; 2) Carry out community outreach to key stakeholders; 3) Develop educational programs to meet members' needs.

Partnership and collaboration play an important role in moving the Strategic Blueprint forward.

a representative of National Government Services led the discussion.

- **Palliative Care Webcast** - HPCANYS partnered with the NYS Department of Health, Cancers Services program and the State University at Albany School of Public Health to present the March 4 webcast, "Palliative Care: Essential to the Patient, the Family and the Public's Health." Hosted by local news anchor, Benita Zahn, the broadcast featured Dr. George Giokas of the Community Hospice of Schenectady and Dr. John Gillespie of the Center for Hospice and Palliative Care in Buffalo. The broadcast was viewed live by over 300 people worldwide and is archived on the School of Public Health web site.
- **Billers' Audio Conference** - HPCANYS hosted a 90-minute audio conference in March 2010 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.
- **Living with Grief® : Cancer and End of Life Care** - On March 24, HPCANYS hosted the broadcast of the Hospice Foundation of America's Seventeenth Annual Living With Grief® Teleconference. Panelists discussed the transition to palliative care, the care of dying persons, professional, volunteer and caregiver needs and the aftermath of cancer death.
- **New Directors Meeting** - Held April 16, 2010, at the NYS Nurses Association, "Fresh Faces, Fresh Ideas" featured several presentations: Virginia

Arbour of Community Hospice spoke on Sound Financial Practice, Jennifer Kennedy of NHPKO informed us of the latest Federal regulatory developments, and experts from the NYS Department of Health described on-going state projects. Finally, the audience engaged in a focused discussion with a panel of experienced program Directors: Bill Finn from Hospice Buffalo, Mary Ann Starbuck from Southern Tier Hospice and Palliative Care, and Ron Watson from The Community Hospice.

*HPCANYS WILL
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Public Engagement and Community Outreach

- Through the Association's toll-free 800 #, information about hospice and palliative care is available to the public on a 24/7 basis.
- In November 2009, HPCANYS published an 8-page insert in the November 10, 2009 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 continues to partner with United Hospice of Rockland to promote, "Assuring Your Wishes," a website providing information and instruction on the completion of advanced directives. www.assuringyourwishes.org encompasses secure on-line storage of data that individuals (and their health care agents and physicians) can access by the click of a mouse. The overall objective of this program is to ensure that individuals' health care directives are documented, known to those who have responsibility for ensuring that they are carried out, and accessible whenever and wherever needed. This service is available to members of the community at no charge. At this time ten New York State counties are participating.
- HPCANYS participated in a national effort to promote April 16, 2010 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.ddhospiceandpalliativecare.org. A monthly e-newsletter and quarterly professionally facilitated on-line discussion forum are available through the website.
- The Hospice Veterans Partnership (HVP) website (www.hpcanys.org/veterans), which provides information to veterans and their families seeking help and services at end of life, is being updated to include advance care planning information, availability of bereavement services and more complete contact information. In 2010 we issued a revised and updated HVP informational brochure.
- HPCANYS' Community Outreach Task Force has 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. These efforts include 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 also developed "tip sheets" for providers on topics such as market penetration and nursing home relations.

Palliative Care Activities

In efforts to increase access to

quality palliative care HPCANYS:

- Researched and identified forty-two hospital-based Palliative Care Providers within New York City and created a working list of active palliative care programs along with their directors.
- Created a needs/strengths assessment tool and began the process of conducting personal assessments with each of these hospital-based palliative care providers in order to understand the barriers, challenges, goals, and needs of these programs while educating them about the mission and activities of HPCANYS and identifying areas where the Association can best support hospital-based palliative care programs in NYS.
- Developed a 'Palliative Care Home Support Pilot' grant proposal that would provide palliative care services to Medicaid-eligible adults in New York State with advanced, life-limiting illness and demonstrate the cost effectiveness of comprehensive home-based palliative care case management. We have identified viable private and public funders interested in promoting palliative care programs in NYS and created an outreach strategy to secure funding for the pilot within the next year.
- The Pediatric Palliative Care Partnership in NYC was revitalized 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.

Donors

Thank you to all who so generously supported HPCANYS' mission, programs and services (based on donations made January 1 – December 31, 2009). 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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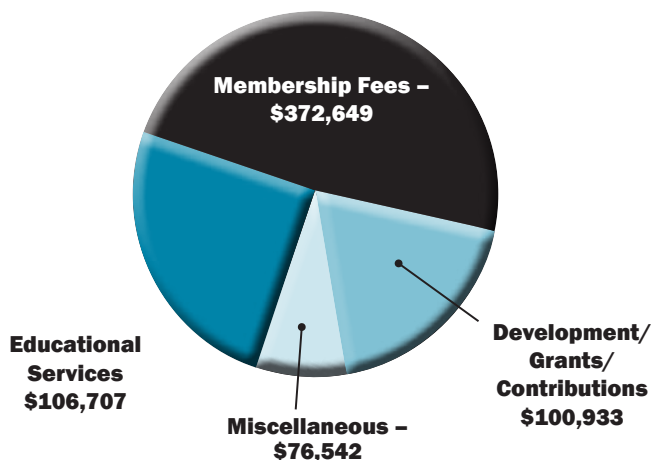
Financial Information

January 1 – December 31, 2009

As is our custom, the financial statement reflects our fiscal year, January 1 – December 31, 2009.

These numbers are in draft form, pending completion of the financial statement audit.

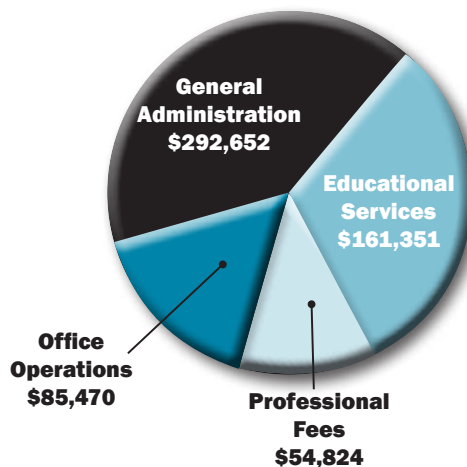
2009 Revenue – \$656,831



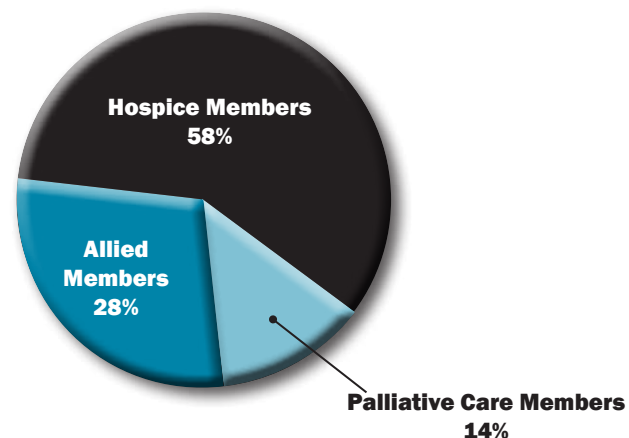
Membership

Hospice Membership	46
Palliative Care Membership	11
Allied Membership	22
Individual Membership	179

2009 Expenses – \$594,297



Provider & Allied Membership



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