



**HPCANYS**

**38<sup>TH</sup>**

**ANNUAL REPORT**

**2017-2018**

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# 2018

## PRESIDENT'S REPORT



It is my sincere pleasure to have joined HPCANYS in 2017 as we navigate and shape our future in New York and nationally! Since June, I have experienced every end of our beautiful and diverse state as I visited programs—hearing about your successes, what you are proudest of, and what challenges you face. We are proud of the care that is delivered in NY State and of the exceptional staff and leadership that provides that care! We are confident, with the Board of Trustees, our members, and our supporters, that we will continue to positively impact legislation, regulation and clinical practice for the benefit of all New Yorkers and their families needing the specialized care of hospice and palliative care.

In 2017, we focused on collaboration and building relationships. We realize the health care system is changing, and we see more new models, like valued based purchasing, bundled services, care across a lifetime, ACO's, Delivery System Reform, Regulatory Modernization Initiatives, and the movement to more post-acute or community-based provider, to name a few. There is greater value in our common causes and speaking in Albany with a common voice. We have had many conversations with the Department of Health to share our collective concerns and solidify hospice and palliative care as essential providers of health care.

HPCANYS, under the strategic direction of the board, has charted a new course for how the Association will operate on a daily basis. Effective January 2018, we created the first of its kind state and national collaboration between HPCANYS and the National Hospice and Palliative Care Organization. This relationship will enhance and strengthen the services and operations of HPCANYS by providing state of the art association management services to the operations. This will allow HPCANYS to remain an independent not-for-profit organization focused exclusively on the needs of hospice and palliative care organizations in New York State.

HPCANYS has provided its members information, education, consultation, and advocacy. We have initiated the Peer Groups this year as a means to do shared work, to promote networking among the hospice providers, and to provide technical assistance. The Association benefits as well, by receiving front line information and examples from the field. You will find more information on our mission and our services in this Annual Report.

Thank you the HPCANYS board and committees who volunteered their time and expertise to help move our agenda forward. Thank you to JoAnn Smith and Sandra Rivera from Rivera Law who helped us successfully have two bills introduced into the NYS Legislature and signed into law by the Governor, one that corrected language about advanced home health aides and one that increased the availability of General Inpatient Care at the Hospice Residences. Together, HPCANYS is an amazing team!

I look forward to the years ahead!

### Carla Braveman

BSN, RN, M.ED, CHCE  
President & CEO

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# PUBLIC ENGAGEMENT AND COMMUNITY OUTREACH

## HPCANYS provides valuable resources to the community

- » Through our toll-free 800 number, information about hospice and palliative care is available to the public on a 24/7 basis.
- » Family Emergency Planning Guides are available to the public.
- » HPCANYS makes referrals to appropriate programs.
- » We answer questions about hospice and palliative care, to support families trying to navigate the healthcare system when a loved one is near the end of life.
- » HPCANYS participated in a national effort to promote April 16, 2017 as National Health Care Decisions Day (NHCDD) via newsletter articles and promoted the event through electronic media

## HPCANYS provides valuable resources to health care professionals

- » HPCANYS continues to promote partnership with Veteran Organizations through our participation in the We Honor Veterans (WHV) program and 45 NYS hospices participate in the WHV program.
- » HPCANYS staff continues to increase understanding of hospice and palliative care by offering educational presentations to a variety of groups. During the past year, HPCANYS' staff have presented to a variety of professional and community organizations, including:
  - Hudson Valley Hospice Veterans Partnership
  - League of Women Voters, Capital Region Tri-County Chapter
  - Upstate Hospice Alliance

## MEMBER SERVICES

### HPCANYS provides support to members through various means

- » In her first year, President & CEO Carla Braveman met with 97% of HPCANYS members at their programs.
- » We have established ongoing peer group conference calls, during which members can discuss issues of emerging importance or use their peers as a sounding board. Current peer groups include:
  - CFO
  - Foundation/PR/Communications
  - Human Resources
  - Leadership
  - Patient Care/Clinical Care/Nursing
  - QAPI/Compliance
  - Social Work/Spiritual Care/Bereavement
  - Volunteer Coordinators

### HPCANYS provides technical assistance to provider members for a wide array of regulatory issues

- » The Hospice Network News (HNN) a member benefit, is published 45-47 times a year by a consortium of state hospice organizations, including HPCANYS. HNN provides summaries of local, state and national news coverage of issues that are of interest to hospice leaders.
- » *The Reporter*, HPCANYS' quarterly newsletter, provides state and federal-level information as well as member updates.
- » For fast-breaking updates, our Director's Memos provide timely dispatches to all provider members. In 2017 – 2018, HPCANYS issued 60+ memos.
- » In collaboration with Hospice Analytics, HPCANYS provides members with the latest statistics on New York State-specific Medicare hospice utilization.
- » HPCANYS staff has provided various lectures on-site at hospice programs – for Board Members, medical and clinical staff.

# EDUCATION

## *Telling Your Story* HPCANYS' 37th Annual Interdisciplinary Seminar and Meeting

The Gideon Putnam Hotel in Saratoga Springs, NY was the site of the Hospice and Palliative Care Association of New York State's (HPCANYS) 37th Annual Interdisciplinary Seminar and Meeting, *Telling Your Story*. Individuals representative of the interdisciplinary team, exhibitors from around the country, and numerous hospice volunteers and honored guests gathered on March 31 for a day of education, interaction, networking and professional renewal. We were pleased to welcome, Stephen P. Kiernan as our Keynote Speaker. Mr. Kiernan, who grew up in the Capital District, is the author of three novels *The Hummingbird*, *The Curiosity*, and *The Baker's Secret*. He has also written two nonfiction books, *Last Rights* and *Authentic Patriotism*. Two of his books, *The Hummingbird* and *Last Rights* deal with hospice and palliative care, through fiction and non-fiction mediums. In his talk, Mr. Kiernan presented new research on end-of-life in New York State, while describing how hospice and palliative care professionals can weave both data and human interest stories to better advocate for their patients and families. The rest of the day offered a selection of 20 workshops addressing topics unique to hospice and palliative care, and designed to address the particular needs of the interdisciplinary team.

## IDD Hospice and Palliative Care Symposium

HPCANYS partnered with Good Shepherd Hospice to present an Intellectual and Developmental Disability (IDD) Hospice & Palliative Care Symposium on July 26, in Long Island. Funded by the Y.C. Ho-Helen and Michael Chiang Foundation, the day brought together community and hospital-based hospice and palliative care providers, and those assisting IDD individuals, including Maryhaven the ARC of Suffolk and the ARC of Nassau. Other attendees and speakers included Mental Hygiene Legal Services, OPWDD, MOLST and the Surrogate Decision Making Committee. The symposium is designed to develop supportive and functional relationships among professionals working with IDD, hospital, and hospice and palliative care systems to ensure improved access to hospice and palliative care services for persons with IDD and their families.

## EDUCATION CONTINUED

### Leadership Institute

Held in Albany, NY, this one-day event geared to directors and emerging leaders in the fields of hospice and palliative care informed and updated members on the latest legislative, regulatory and programmatic changes occurring both statewide and nationally. Speakers and presentations included Edo Banach, the President and CEO of NHPCO, Cordt Kassner, of Hospice Analytics, and Margaret Willard and Diane Jones, from the NYS Department of Health, Office of Primary Care and Health Systems Management, Division of Home and Community Based Services. Finally, we were joined by Elizabeth Amato, Senior Director, Statewide Services of the New York eHealth Collaborative and Deirdre Depew, Research Scientist with the NYSDOH Office of Quality and Patient Safety. Their presentation explored SHIN-NY (the Statewide Health Information Network for New York) a State of New York initiative to develop a secure network for sharing electronic clinical records.

### Pediatric Palliative Care

In November, HPCANYS delivered a two-day training, based on HPCANYS' Interdisciplinary Pediatric Palliative Care curriculum. The event, held at the Sagamore, in Lake George, offered ten intensive modules focused on the particular needs of caring for children at end of life. Our Children's Hospice and Palliative Care Advisory Group is currently working on a 201 version of this acclaimed curriculum.

### Hospice Strategic Growth Program

On January 24, HPCANYS presented a Hospice Strategic Growth program, a collaboration with Simone Healthcare Consultants. Wayne Regan, Director of Interim Management Services at Simone, provided a full-day hospice-specific sales, marketing and strategic growth workshop. The following day, HPCANYS hosted a Peer Group meeting for hospice business development personnel, to further reflect on what was discussed in the prior day's workshop and plan for the future. Simone also extended to HPCANYS members attending the January 24 event the opportunity to engage Simone in a custom Hospice Marketing and Sales Management Consulting Package at a deeply discounted rate.

### Billers Audioconference

HPCANYS hosted a 90-minute audio conference in January facilitated by Corrinne Ball, Medicare Provider Outreach and Education Consultant, who gave an update on National Government Services (NGS) activities, general billing and what's new with Hospice.

### Webinar Series

In 2017 – 2018 HPCANYS provided members with a series of non-clinical webinars featuring nationally recognized speakers addressing a variety of non-clinical topics. 57 webinars were offered in 2016 – 2017, including several multi-part "Series," including: the Leadership Series; the Volunteer Manager Series; the Prudent Hospice™ Approach to Live Discharge Series; the Survey Series; the Hospice Billing Series and the Compliance Series, as well as a 6-module on-demand, subscription-based On-Line Volunteer Training program.

## ACCESS TO QUALITY HOSPICE AND PALLIATIVE CARE

### Advocacy/Public Policy

The many accomplishments of HPCANYS' advocacy team—State Legislative & Regulatory Committee, Federal Legislative & Regulatory Committee and Government Relations Consultants Sandra Rivera and JoAnn Smith—are to be applauded. Despite a challenging regulatory and legislative environment, HPCANYS has spearheaded many successful endeavors.

#### IN NEW YORK STATE...

- » Two bills (hospice residence bill and the technical amendments to the hospice home care worker registry bill) introduced at the request of HPCANYS became law in 2017. A.7775/S.6364 increases the number of beds which can be certified for both routine home care and general in-patient from 25% of all beds to 50%. HPCANYS will now work with the Department of Health on implementing the regulations that support this new legislation. A.7846/S.6347 is a technical amendment of the 2016 Advanced Home Health Aide legislation. Last year's bill subjected hospice home health aides to the requirements of the home care services worker registry. This bill clarifies that hospice programs are considered home care services entities only for the purpose of compliance with the registry. Additionally, the bill provides that a hospice may provisionally employ a home care worker while a background check is pending. This bill has passed both houses and has been signed into law by the Governor. The Department of Health is currently working on drafting regulations to implement all facets of the Advanced Home Health Aide legislation and HPCANYS has been in continuous conversation with the Department as they proceed.
- » Another bill, sponsored by MJHS and supported by HPCANYS, to increase the Hospice Residence rate, was passed by both houses, but vetoed by the Governor. We were pleased to see this measure included in the Governor's proposed 2018-2019 budget and will continue to advocate for this measure to be included in the final adopted budget.
- » HPCANYS has devoted a considerable amount of time to marshalling resources to oppose Governor's 2018 Budget proposal of a 2¢ per ml surcharge on opioids.
- » Included in the Governor's budget proposal was an initiative to expand Advance Care Planning. HPCANYS has met several times with legislators and DOH officials to show our support for this proposal and offer our expertise as this venture takes shape.
- » We have been actively monitoring the Public Health and Health Planning Council as they confer on the Regulation Modernization Initiative. HPCANYS is pleased to have secured a spot on this Task Force and we will continue to advocate for the best interest of our members as the RMI examines Certificate of Need.

- » HPCANYS members joined LeadingAge New York for our joint February 2018 Advocacy Day in Albany and visited over 30 Senators and Assembly Members. HPCANYS' focus was the hospice proposals in the Governor's proposed budget.
- » We continue to work with the Department of Health as they develop guidance for Advance Home Health Aides, including identifying questions to be included in DOH's FAQs.
- » HPCANYS remains committed to working with DOH on hospice guidance for Medicaid Managed Long Term Care Plans. We have met multiple times with several departments within the Department of Health and continue to communicate our members' concerns.
- » HPCANYS has been an active presence at many DOH-convened meetings and workgroups, including: the Future of Integrated Care, the Children's Medicaid System Transformation, Value Based Payments Roadmap, the Regulatory Modernization Initiative, the Long Term Care Need Methodology & Innovative Models, and Post-Acute Care Management Models Work Group.

### FEDERAL LEGISLATION & REGULATION...

- » HPCANYS submitted substantial comments to the Centers for Medicare & Medicaid Services (CMS) on Wage Index & Payment Rate Update. This letter of comment covered hospice payment reform, including research and analysis, as well as updates to the Hospice Quality Reporting Program, pre-Hospice spending and public display of hospice data.
- » We continue to monitor MedPAC's recommendations regarding hospice, including carving hospice into Medicare Advantage, as well as changes in hospice reimbursement.
- » In July 2017 legislative visits were made to members of Congress to share HPCANYS' Issues Paper focusing on hospice reimbursement cuts, CMS's unfunded mandates, and the concern that hospice statute is being "rewritten" via regulation.

### Innovation and Partnerships

Effective January 2018, HPCANYS and NHPCO entered into a strategic relationship to enhance and strengthen the services and operations of HPCANYS by providing state of the art association management services to the operations. This allows HPCANYS to remain an independent not-for-profit organization focused exclusively on the needs of hospice and palliative care organizations in New York State.

With support from the Ho Chiang Foundation, HPCANYS continues to partner with NYSARC and Mental Hygiene Legal Services (MHLS) as well as IDD and Hospice & Palliative Care provider systems to develop effective cross-systems education and promoting best practice principles for the delivery of palliative and end of life care for all persons with developmental disabilities.

The Association maintains a strong affiliation with LeadingAge New York. In February, 2018 HPCANYS collaborated with LeadingAge on a joint advocacy day at the State Capitol. We are currently working with them on a senior services workforce project, examining the capacity of our current system to provide care for the coming age boom. Members of each association can also access programs and services of each association at no additional cost, including pricing on contracts through ValueFirst, the LeadingAge group purchasing organization.

HPCANYS continues to meet with both LeadingAge NY and the Empire State Association of Assisted Living- as well as with key influencers in the Department of Health - to discuss strategies for removing barriers to providing hospice in Assisted Living or Adult Care Facilities.

In November, we supported the ARC of New York with the planning and implementation of their annual Guardianship Symposium. HPCANYS worked closely with the planning committee of the Guardianship Program to ensure that end-of-life issues were included in the training, "Changing the Story: Guardianship and Evolving Alternatives."

### In addition, we are honored to work with:

- » Center to Advance Palliative Care (CAPC)
- » Healthcare Association of New York State (HANYS)
- » Home Care Association of New York State
- » National Government Services (NGS) and its POAG Group
- » National Hospice and Palliative Care Organization (NHPCO) and its Council of States and Pediatric Palliative Care State Leaders Network
- » New York Chapter, American College of Physicians
- » New York State ARC
- » New York State Department of Health
- » New York State Health Facilities Association
- » New York State Palliative Care Education and Training Council
- » New York State Tribute Foundation
- » New York Statewide MOLST Implementation Team
- » Upstate Hospice Alliance
- » Veteran's Administration

### HPCANYS 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

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## HOSPICE HERO: The Connie Raffa Memorial Fundraiser

On September 14, HPCANYS held the first Hospice Hero: The Connie Raffa Memorial Fundraiser. Supporters gathered from all over the state – and

tri-state area- at the downtown New York offices of event co-sponsor, Arent Fox, to celebrate the legacy of our dear friend, Connie Raffa. Connie's dedication to her clients and her legendary battles to "do the right thing," inspired us to dedicate an annual fundraiser to her memory. Her life's work, the Sisyphean task of battling entrenched institutional obstacles so that all people could have access to the best care, truly qualifies her as the original Hospice Hero. Dr. Russell Portenoy, Executive Director of the MJHS Institute for Innovation in Palliative Care and Chief Medical Officer of MJHS Hospice and Palliative Care, was the recipient of the first Hospice Hero Award.

## FINANCIAL INFORMATION

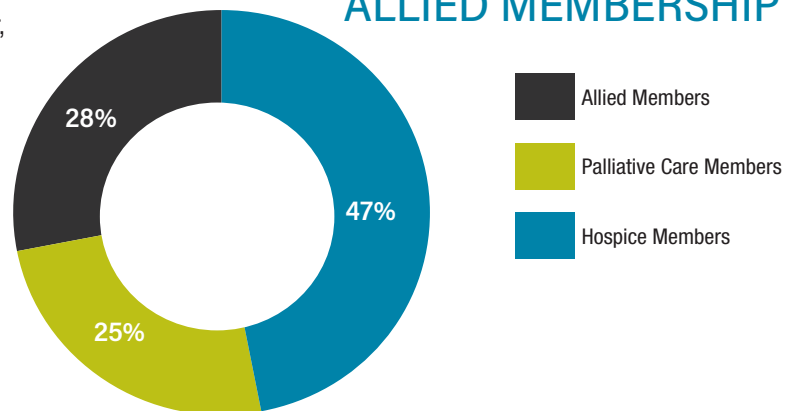
January 1 - December 31, 2017

As is our custom, the financial statement reflects our fiscal year, January 1 - December 31, 2017. These numbers are in draft form, pending completion of the financial statement audit.

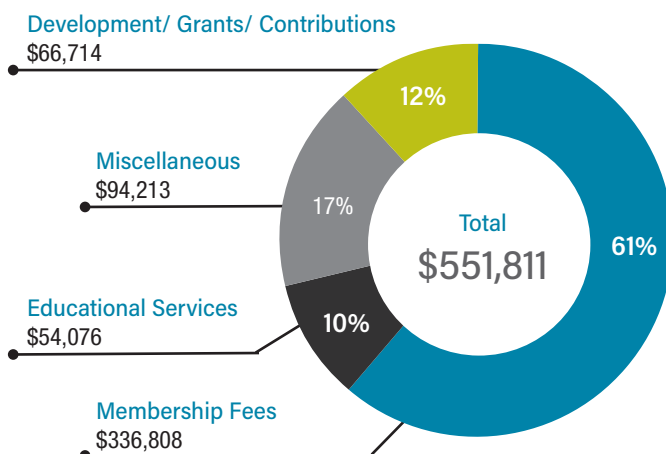
### MEMBERSHIP

Hospice Membership .....	36
Palliative Care Membership.....	19
Allied Membership .....	22
Total .....	77

### PROVIDER AND ALLIED MEMBERSHIP



### 2017 REVENUE



### 2017 EXPENSES

