Gearing Up for Hospice Advocacy in 2012

With every member of the House of Representatives, one third of the Senate and the White House up for election in 2012, the new year is going to be another political nail-biter—especially with issues like the national budget crisis and entitlement reform hanging in the balance. So what does this mean for hospice advocacy?

It means that engaging members of Congress, both on the Hill and in their home states, is going to be even harder than last year. While the summer months are generally the height of legislative activity during any Congressional session, the elections will make June and July more eventful and action-packed.

To make sure “the voice of hospice” is heard through the noise, NHPCO and its affiliate, the Hospice Action Network (HAN), are offering two opportunities to help members hone their advocacy skills, network with colleagues, and begin building or developing relationships with members of Congress. And they’re making both events free for NHPCO provider-members and staff.
On March 27 and 28, NHPCO and HAN will host their fourth annual Hill Day, being held in conjunction with the Management and Leadership Conference at the Gaylord National Hotel and Convention Center (just eight miles from Capitol Hill). Each year this event gets better, and this year is no exception. Based on feedback from participants, Hill Day 2012 will include new virtual strategy sessions that will be offered in advance of the event.

Then on June 18 and 19, the HAN Advocacy Intensive will be held, also in Washington, at the historic Washington Court Hotel (which is literally in the shadow of the U.S. Capitol). There will be high-level concurrent sessions, a Congressional staff panel, and a Congressional keynote address, plus a Pep Rally to kick off meetings on the Hill. This Intensive is designed for leaders, staff and advocates at every level—board members and senior leadership, interdisciplinary team members, volunteers, and even patients and families.

Here is an overview of the two opportunities so you, your staff and your hospice supporters can plan for and, hopefully, attend one or both.

- Get a political ‘snapshot’ of the current Hill climate and how it relates to hospice care back home (information that’s helpful for meetings on the Hill as well as meetings with your board).
- Hear directly from key Hill staff during a panel discussion on best practices (e.g., communicating with members of Congress during site visits, meetings, and other situations).
- Attend an evening dinner, with a keynote address by a current member of Congress.
- Network and participate in message coordination sessions.

New HAN Advocacy Intensive
June 18 and 19, 2012

Being held just two blocks from the U.S. Capitol at the Washington Court Hotel, this two-day conference will focus exclusively on Hospice Advocacy, and teach best practices that you can use when interacting with members of Congress. And, as noted earlier, any and all members of the hospice community are encouraged to participate, from clinicians to development managers to volunteers.

Over the course of two days, participants will:

- Attend an evening dinner, with a keynote address by a current member of Congress.
- Network and participate in message coordination sessions.

continued on page 4
One of the projects that NHPCO is widely recognized for is the annual report, *Facts and Figures: Hospice Care in America*. This report provides an overview of trends in the growth, delivery, and quality of hospice care at the national level. A wide variety of statistics related to patient and provider characteristics are presented, as well as information on length of service, location and level of care, and staff and volunteer commitment.

This highly regarded document is used by providers, others in the healthcare community, regulators, legislators and the media. NHPCO’s ability to make it available to the public affirms our role as a leadership organization.

Every year we improve the report, building on the previous year’s edition. Two additions to this 2011 edition include sections on hospice use by Medicare beneficiaries and those within the nursing home population. Also new is an appendix that details the accuracy of NHPCO’s national estimates.

The NHPCO Research Team works incredibly hard to bring together data—from many sources—to provide this comprehensive look at hospice care. The data come from state health and hospice associations, the Medicare Provider of Service file from CMS, and provider-member submissions to NHPCO’s annual National Data Set. All of you who participate in the National Data Set are an important part of the process. For your commitment and participation, I extend my deepest appreciation.

If you have not read the report yet, please download a copy from the NHPCO website. It is featured in the News Room as well as in the Research section of the website. In next month’s issue of *NewsLine*, we will also look a bit more closely at some of the findings.

J. Donald Schumacher
President/CEO
with other attendees from your state who share similar concerns, challenges and goals.

- Re-energize at a Pep Rally—with all attendees and some surprise guests. (The Rally is also a great opportunity for photos that can be used in newsletters and local media outreach.)

- Meet with members of Congress (to be scheduled beforehand by HAN staff).

During the Advocacy Intensive, participants will also have the opportunity to attend one of three concurrent educational sessions, each focusing on a different aspect of Hospice Advocacy:

**In-District Advocacy Session**
This session will provide the basics on how to build on the work you are doing on Capitol Hill once you return home, such as planning a tour of your program with your members of Congress, becoming a ‘go-to’ source for him or her, and creating video testimonials. You’ll also learn how to implement these initiatives with minimal staff or material resources and develop strategies to translate your advocacy into something that will stand out in your community. (This session is an ideal choice for those interested in grassroots activity and for first-time HAN attendees.)

**Media Advocacy Session**
This session will show you how to get positive stories placed in your local media about your interactions with members of Congress, along with tactics to help raise the profile of hospice in your area.

**Lobbyist Roundtable Session**
This session convenes a bipartisan panel of HAN lobbyists to provide insights for the seasoned Hospice Advocate. Drawing on 50 years of collective experience as senior-level Hill staffers and consultants, the panel will discuss the current political environment and how to best leverage your advanced relationships with congressional offices into tangible advocacy results.

**Registration is Free, But Limited—So Book Early**
While participants will be responsible for their travel and hotel accommodations, there is no charge for attending the HAN Advocacy Intensive. However, space is limited to 250 attendees—
so please be sure to book early. Registration will open in March. To learn more now, send an email to info@nhpcohan.org.

When planning your trip, consider staying a few extra days. You can enjoy the sights of the city and rub elbows with DC insiders at one of the many power spots around the The Washington Court Hotel and Capitol. (HAN staff will be happy to offer suggestions.) You will also be just blocks away from the National Mall—near several of the Smithsonian museums and many of our nation’s monuments.

Hill Day 2012
March 27 and 28, 2012

This annual advocacy event is, once again, being held in conjunction with the Management and Leadership Conference at the Gaylord National Hotel and Convention Center.

Each year, as part of Hill Day, HAN hosts specific training sessions on the first afternoon of the event to help Hospice Advocates better understand the “Hill process” and coordinate their messaging. Hill meetings then take place on the second day. Feedback from Congressional offices consistently emphasizes that the extra training and messaging coordination really pays off, with the hospice community making a strong impression during their meetings on the Hill.

So this year, NHPCO and HAN will offer two strategy sessions in advance of Hill Day—in the convenient form of Webinars. Webinar dates and times (ET) are as follows:

**Hill Meeting Fundamentals:**
March 13 (2 p.m.); March 14 (6 p.m.); or March 19 (1 p.m.)

**Communicating with Congress: How to Turn a 10-Minute Meeting with a Legislator into a Life-Long Relationship:**
February 23 (6 p.m.); March 7 (1 p.m.); or March 13 (3 p.m.)

Other Important Notes
Hill Day registration will begin at 5:00 p.m. on Tuesday, March 27, with time in the evening for Hospice Advocates to meet one another. Of course, HAN will also have its Hospice Respite Room in the Capitol Visitor’s Center to offer Hospice Advocates the chance to compare notes, debrief, and relax and reenergize before, in between or after the day’s Hill meetings.

NHPCO and HAN also want providers to know that the National Association of Home Care
Why We Travel Half Way Around the World for Hill Day

Imagine traveling for 15 hours in a crowded airplane, center row, between talkative seat mates when all you want to do is rest! From Hawaii, there is no such thing as a quick trip to DC. It is more like traveling a quarter of the way around the world, and then back again. So why do my colleagues and I from Hawaii make the trek every year, allowing enough time to attend both Hill Day and MLC?

It's simple really. Politics is about relationships—or as the former Speaker of the House, Tip O’Neill, used to say, “All politics is local.”

We try to meet with our members of Congress when they are on the islands. We attend their fundraisers and we make sure that we connect with their staff. But we attend Hill Day because it really shows that the event, and what it represents for constituents, is *that* important.

We have found that our representatives and their staff already know, intellectually, about hospice from our ongoing contact and the briefings they receive from NHPCO and HAN. But during Hill Day, we touch their hearts. We bring them the personal stories and remind them that we are changing lives back home. We are bringing hope to what may seem like a hopeless situation, one family at a time. Families that are all their constituents—with some even being their neighbors, their friends and, perhaps, part of their own family.

It is a long flight and, inevitably, there is always a young child behind me who likes to kick my seat. But in the end, we make the trip because it makes a difference to those we serve.

Kenneth L. Zeri, RN, MS, NHA
President/Chief Professional Officer
Hospice Hawaii, Inc
Learn more and register at www.nhpco.org/MLC2012

March 29-31, 2012

Preconference Seminars and Capitol Hill Events: March 27-28, 2012
Main Conference: March 29-31, 2012

Hospices are facing a multitude of regulatory, economic and legislative challenges. The 27th MLC gives you the tools you need to LEAD your organization through changes occurring in the healthcare landscape.

The 27th Management and Leadership Conference and 8th National Hospice Foundation Gala

IT’S ABOUT HOW WE LEAD

The National Hospice and Palliative Care Organization presents:

LISTEN

ENGAGE

ADVOCATE

DEFINE

NewsLine 7
If you are reading this article, chances are good that you already have some degree of interest in better serving lesbian, gay, bisexual, and transgender (LGBT) patients. Or perhaps you’ve never cared for an LGBT patient and you are curious about their “special” needs? Whatever your reason, the very fact that you are reading this article shows your interest in expanding your capacity to better serve everyone in your community who needs end-of-life care.
First, let’s talk terminology. In this article, “LGBT individual” refers to a person who self-identifies as lesbian, gay, bisexual or transgender:

Lesbian women and gay men are individuals who self-identify as being attracted primarily to members of their own gender, while bisexual men and women are individuals who self-identify as being attracted to members of both genders. Just like their heterosexual counterparts, they also exercise a wide range of relationship choices and, as such, may be single, partnered in a monogamous relationship, partnered in a non-monogamous relationship, married, widowed, separated, or divorced. When we say a person is straight (heterosexual), gay, lesbian, or bisexual, we are referring to a person’s sexual orientation.

Transgender individuals, on the other hand, refer to people whose inward sense of their gender—their gender identity—is discordant with the gender assigned to them at birth. For example, a person who was assigned the male gender on his birth certificate, but feels strongly that their gender is female, is considered a transgender individual. These individuals may have the genitalia and reproductive organs they were born with, or they may not. They may take hormones, or they may not. They may live full-time as their chosen gender, or they may not. Healthcare professionals should never make assumptions when it comes to gender identity and its impact on an individual patient’s health—every patient is different. Another thing to remember is that gender identity isn’t the same thing as sexual orientation. A transgender individual may be straight, gay, lesbian, or bisexual.

All of this may seem confusing and if it does, you’re not alone. Sexual orientation and gender identity are complex constructs that aren’t easy to make sense of. I can’t tell you how often I’ve heard someone wonder aloud, “What if a person is born a girl, identifies as a man, and then falls in love with a man? Is that person gay or straight?” Or, how about this old chestnut: “Are people born gay? Or is it a choice?”

continued on next page
While these are valid questions to ponder, they are the wrong questions for hospice and palliative care professionals to ask when it comes to meeting the needs of LGBT patients and families. So what are the right questions to ask? How do you provide these individuals with high-quality end-of-life care? Here are a few simple guidelines:

**Make No Assumptions**
If an individual identifies him or herself as “single” and lives with a person of the same gender, it doesn’t necessarily mean that the individual is gay or lesbian. Similarly, if someone is married to a person of another gender, it doesn’t mean he or she is heterosexual. Nor do the genitalia and reproductive organs we were born with always indicate our gender identity. When in doubt, ask your patient what you need to know—assuming that what you want to know is needed for clinical reasons and not just to satisfy your curiosity. For example, knowing whether transgender patients are on hormones has clinical relevance to their care; knowing their age when they realized they were transgender does not. Remember, your patient has come to you for care, not to be your teaching moment. Respect that fact and only ask what you actually need to know to meet that patient’s needs at the end of life.

**Make No Judgments**
Your role is to care for the patient and family, not to pass judgment. Who your patient chooses to love, live with, or marry is his or her business. Your business is to make sure you treat patients—and the individuals they consider to be their friends and family—with dignity, respect and compassion. To do anything less would be unprofessional.

**Remember to Keep Your Opinions to Yourself**
This is closely related to “making no judgments”—but it is so important, it bears repeating. For example, if you have religious beliefs about homosexuality, do not share those beliefs with your patients. Ever. The most well-intended comment can cause dying patients or their grieving family and friends a great deal of emotional pain during an already difficult time in their lives. If you have strong religious convictions, remember to withhold them, adhering to professional boundaries.

Your role as a hospice or palliative care professional is to provide the highest quality care to each patient you serve, regardless of whether their values, beliefs and life experiences are similar or different than your own. You know
this already—I’m not telling you anything you haven’t heard before. But what does this mean on a practical level?

“Meeting patients where they are” is easy when their lives look similar to yours, but what about when their lives look much different? How do you ensure that you meet all your patients where they are, without prejudice or judgment? If a lesbian patient is admitted to your hospice or palliative care program, do your personal theories (e.g., “she must have turned gay because of a bad experience with a man”) and religious beliefs (e.g., “homosexuality is an abomination”) end up influencing the way you treat that patient? How can you know for sure that they don’t? These are the questions you need to be asking. Coming up with answers to these questions is just as hard as answering questions about the origins of homosexuality, but infinitely more valuable in terms of ensuring the provision of high-quality end-of-life care.

Kimberly D. Acquaviva is an assistant professor of nursing and director of The National Collaborative on Aging at The George Washington University School of Nursing. She is also a noted authority on LGBT aging, and serves on the editorial boards of Sexuality Research and Social Policy, Journal of Gay and Lesbian Social Services, and Journal of Ethnographic & Qualitative Research.
NHPCO’s National Council of Hospice and Palliative Professionals (NCHPP) is comprised of 48,000 staff and volunteers who work for NHPCO provider-members. Organized into 15 discipline-specific sections that are led by the NCHPP chair, vice chair and 15 section leaders, NCHPP represents the perspectives of the interdisciplinary team—the very essence of hospice care.

These individuals—together with each Section’s Steering Committee—volunteer their time and expertise to a variety of NHPCO projects to help preserve and develop the “interdisciplinary model” within the evolving world of hospice and palliative care.

In this NewsLine feature, we shine the light on a different NCHPP Section each month, so all members can benefit from each discipline’s perspective on important topics. It will also help members learn more about the work of NCHPP and how to get more involved—whether it’s taking better advantage of some of the Section’s free activities or joining a Section’s Steering Committee.

This month we spotlight the NCHPP Spiritual Caregiver Section, and an article by Bonnie Meyer….
The benefits of using simple, numeric tools (such as the PPS, the Pain Level, and the Edmonton Scale) as a part of hospice and palliative care assessments are clear. Numeric tools provide measurements which inform and improve four important aspects of patient care: triaging and care planning, interdisciplinary communication, reporting, and research.

The development of tools to measure psychosocial-spiritual suffering has been a very slow and challenging process for several reasons. There is a lack of consensus on definitions for spirituality and spiritual suffering both in academic circles and in the general population (i.e., “conceptual inconsistency”).

There is resistance on the part of many professional chaplains to embrace a goal of “measurable outcomes” which, in turn, results in their failure to produce these tools. And finally, there are the difficulties that one encounters when trying to measure the psychosocial-spiritual aspects of care (i.e., “operational difficulties”).

A Consensus Conference on Improving the Quality of Spiritual Care in Palliative Care, held in Pasadena, California in 2009, was an important step forward. Many leaders of the effort to improve spiritual care in healthcare participated in this conference, including physicians, researchers, nurses, social workers, chaplains and theologians. However, while the conference participants succeeded in developing a consensus definition of spirituality and an initial listing of spiritual diagnoses and treatments, they did not create any assessment tools.

HOB’s Spiritual Suffering Scale

Hospice of the Bluegrass (HOB), based in Lexington, Kentucky, has a history of valuing quality spiritual care and was one of the earliest hospices to make a commitment to hiring professional chaplains to provide spiritual care for our patients.

In 2007, a spiritual care committee at HOB surveyed the literature for existing spiritual assessment tools, and determined that there was a need for a simple, numeric scale as a measure of spiritual suffering. With the involvement of over 40 professional chaplains, a draft was created and then tested for two years. A revised version was implemented in April of 2010 to produce the scale that I present here.
### Spiritual Suffering Scale

<table>
<thead>
<tr>
<th>Score</th>
<th>Distressing Factors</th>
<th>Minimal Distressing Factors</th>
<th>Moderate Distressing Factors</th>
<th>Severe Distressing Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Minimal distressing factors</td>
<td>Little focus on distress</td>
<td>Moderate distressing factors</td>
<td>Little focus on distress</td>
</tr>
<tr>
<td>2</td>
<td>Minimal distressing factors</td>
<td>Some focus on distress</td>
<td>Moderate distressing factors</td>
<td>Some focus on distress</td>
</tr>
<tr>
<td>3</td>
<td>Minimal distressing factors</td>
<td>Distress dominating focus</td>
<td>Moderate distressing factors</td>
<td>Distress dominating focus</td>
</tr>
<tr>
<td>4</td>
<td>Moderate distressing factors</td>
<td>Little focus on distress</td>
<td>Moderate distressing factors</td>
<td>Little focus on distress</td>
</tr>
<tr>
<td>5</td>
<td>Moderate distressing factors</td>
<td>Some focus on distress</td>
<td>Moderate distressing factors</td>
<td>Some focus on distress</td>
</tr>
<tr>
<td>6</td>
<td>Moderate distressing factors</td>
<td>Distress dominating focus</td>
<td>Moderate distressing factors</td>
<td>Distress dominating focus</td>
</tr>
<tr>
<td>7</td>
<td>Severe distressing factors</td>
<td>Little focus on distress</td>
<td>Severe distressing factors</td>
<td>Little focus on distress</td>
</tr>
<tr>
<td>8</td>
<td>Severe distressing factors</td>
<td>Some focus on distress</td>
<td>Severe distressing factors</td>
<td>Some focus on distress</td>
</tr>
<tr>
<td>9</td>
<td>Severe distressing factors</td>
<td>Distress dominating focus</td>
<td>Severe distressing factors</td>
<td>Distress dominating focus</td>
</tr>
<tr>
<td>10</td>
<td>Severe distressing factors</td>
<td>Inability to experience relief</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:**

1. Identify distressing factors arising out of spiritual and religious issues.
2. Determine level of distress: Minimal, Moderate, or Severe.
3. Determine amount of focus on the distress: Little, Some, or Dominating.

**If Assessing Non-verbal Persons or Those with Dementia:**

1. Determine level of distress:
   - Minimal = no observable signs of distress; calm or pleasantly confused.
   - Moderate = observable signs of moderate distress: mild agitation, occasional calling out, irritation.
   - Severe = observable signs of severe distress: agitation, constant calling out, anger.
2. Determine amount of focus on the distress: Little, Some, or Dominating.
We have found that the use of this scale has improved the triaging of chaplain visits, interdisciplinary communication, and reporting within our agency. Initial studies of the scale have also shown that average spiritual suffering levels are higher for younger patients, which would be the expected result. However, further work is needed to determine the reliability and validity of the scale.

It is also important to note that the HOB Spiritual Suffering Scale is a clinician assessment tool. The rating must be done by a professional chaplain because this tool requires the skill of diagnosing the sources of spiritual distress. [For those hospices which do not employ professional chaplains, the patient self-assessment that was shared by Gary Gardia in the July 2011 issue of Newsline would be a more appropriate choice.]

The Three Steps in Using HOB’s Scale

Step One
The chaplain or professional spiritual caregiver begins by identifying the distressing factors which are sources of spiritual distress. There are differing methods which can be utilized to identify these factors (i.e., questions or narrative).

At HOB, we use a narrative format and offer a template (at right) to assist chaplains in identifying the distressing factors that are sources of spiritual distress. However, it is not necessary to use this template; any spiritual assessment which identifies the spiritual problems or sources of spiritual distress can be used with this Spiritual Suffering Scale.

HOB Template for Identifying Sources of Spiritual Distress

Definitions:
“Spirituality” is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.6

“Spiritual Pain” is defined as emotional distress due to spiritual and religious issues.7

Examples of Distressing Factors:
Related to theological and belief issues:
• Inability to participate in usual religious practices
• A belief that God is punitive
• Incongruence between experience and belief
• Troubling beliefs about dying, death, or afterlife
• Inability to hold to beliefs that once brought comfort
• Beliefs that are preventing reconciliation among loved ones

Related to existential and meaning issues:
• Lack of sense of meaning concerning the illness
• Loss of a sense of meaning in one’s life
• Loss of role which gave meaning
• Loss of a sense of hope, grief, and anger
• Difficulty in letting go of futile hopes in order to embrace new hopes
• Loss of a sense of dignity
• Loneliness

Related to relationship issues:
• Difficulties in relationship with God or the transcendent
• Sense of God’s absence or failure
• Sense of a need for forgiveness
• Difficulties in relationship with loved one
• Broken relationships
• Sense of need to forgive or be forgiven, or to forgive or let go
• Difficulties in relationship with one’s sense of self
• Negative sense of self-value
• Sense of shame
• Feelings of guilt or regret in life lived
**Step Two**
After identifying the distressing factors, the chaplain or professional spiritual caregiver makes an assessment of whether the patient’s distressing factors are typical, less than typical, or more than typical for someone who is dying.

**Step Three**
The chaplain or professional spiritual caregiver then assesses if the distressing factors are the dominant focus; if the patient focuses some attention on the distressing factors and some attention on sources of spiritual comfort; or if the sources of comfort are the dominant focus. Thus the scale moves from right to left and ends up with a numerical rating.

Consider, for example, a 36 year-old mother of two teenagers who is quietly angry at God for not healing her, but also works hard to embrace the positives (e.g., her church and family support).

- In Step One, we would identify her distressing factors as the inability to hold to beliefs that once brought comfort (God as healer); anger and the loss of a sense of hope for her own healing; and distress over leaving her children without a mother.

One of the best ways to exchange ideas and tips with your colleagues is through the NCHPP Spiritual Caregiver eGroup on NHPCO’s professional networking site, My.NHPCO. (It’s free for staff and volunteers of NHPCO provider-members.)

Each NCHPP Section has an eGroup on My.NHPCO (much like the former listserves, but better), plus an eLibrary where members post helpful information and resources to help one another.

*If you’re not already a My.NHPCO user, visit the homepage and see “Getting Started” in the top right corner. For specific questions, contact the NHPCO Member Services Department at 800-646-6460 (8:30 a.m. to 5:30 p.m., ET).
• In Step Two, we would identify that she has more than the typical distressing factors and, thus, she would fall in the bottom third of the scale.

• In Step Three, we would assess that she focuses both on the distress and the comfort and, thus, she would be assessed as having a spiritual suffering level of eight.

In Summary
While there is a need for more testing and possible refinement, the HOB Spiritual Suffering Scale represents an effort to move forward despite the difficulties in defining and measuring spiritual distress. A simple numeric measure of spiritual suffering accommodates improved patient care and care planning, improved interdisciplinary communication, and improved avenues for reporting and for research related to spiritual care.

Bonnie Meyer has worked in hospice for 17 years, including 12 years as a hospice chaplain, and five years in her current role as director of spiritual care for Hospice of the Bluegrass. She is board-certified by The Association of Professional Chaplains, and is an ordained minister in the Unitarian Universalist Association. She also serves as NCHPP’s Spiritual Caregiver Section leader.

References
1 The theoretical basis for a biopsychosocial-spiritual model of care was developed by Daniel P Sulmasy. Sulmasy DP: A biopsychosocial-spiritual model for the care of patients at the end of life. Gerontologist 42(Spec No 3):24–33, 2002.
7 This definition and this template of sources of spiritual distress were created by Jason Meyer, who is currently in the medical scientist training program at the University of Kentucky.

Join the Spiritual Caregiver Section for Monthly Chats
Each month, the NCHPP Spiritual Caregiver Section holds “chats”—or conference calls—which are open to NHPCO members.* They provide an opportunity for professional hospice chaplains and spiritual caregivers to share information related to their roles on hospice and palliative care teams.

When Chats are Held:
The first Thursday of each month, from 3:00 to 4:00 p.m. (ET).

To Join the Chat:
Call 866-355-8646. However, please do NOT dial in earlier than 2:55 p.m. (ET) on the day of the call.

*In order to join a chat, you must first be enrolled as an NCHPP member (which is free to all staff and volunteers of NHPCO provider-members). If you are not yet enrolled, call the NHPCO Member Services Department at 800-646-6460.
In conjunction with
NHPCO’s 27th MANAGEMENT AND LEADERSHIP CONFERENCE

THANK YOU TO OUR SPONSORS*

Tanzanite Sponsor

hospice pharmacia
a service of excellRx, Inc.

Amethyst Sponsors
Chapters Health System
Community Health Accreditation Program
Evercare Hospice & Palliative Care and Hospice Inspiris

Garnet Sponsors
The Corridor Group and Jeannee & Mike Martin
Deyta
The Elizabeth Hospice
Studer Covenant
Alliance/Covenant Hospice, Inc.

Friday, March 30, 2012
Gaylord National Resort & Convention Center
National Harbor, Maryland

6:30pm
Cocktails and Silent Auction

7:30pm
Dinner, Awards and Live Auction
Dancing and Dessert to follow

*Sponsors as of January 10, 2012
In this monthly feature, *NewsLine* shines the light on a hospice organization which has expanded services or has partnered with other community organizations to reach patients earlier in the illness trajectory—before they may need hospice care. In a Q&A format, members hear firsthand from the organization’s senior leaders who speak directly to the challenges, the benefits, and the lessons learned.
While access to underserved populations is improving, African Americans still rank among the nation’s most underserved groups. According to NHPCO’s latest Facts and Figures, just 8.9 percent of patients served in 2010 were African American even though African Americans represent 13.6 percent of the U.S. population (2010 National Census Report).

Transitions, a new program of Family Hospice and Palliative Care (FHPC), just launched in February 2011, is aiming to change that, at least in the African American neighborhoods of Pittsburgh’s Greater North Side.

Working in partnership with Bidwell United Presbyterian Church and the North Side Christian Health Center, FHPC’s program focuses on dispelling misconceptions about hospice and palliative care while also helping families enroll seriously ill loved ones on services to help address their suffering and provide home support.

In the following interview, Transitions coordinator, Rev. De Neice Welch, discusses the program and the impact she’s seeing so far.

How did you become involved in FHPC and, now, in this new venture?
I’m the pastor of Bidwell United Presbyterian Church and first became involved in this project while a member of the FHPC board of directors. During a strategic planning process, the board discovered an opportunity to focus on the African-American community residing in Pittsburgh’s North Side. After holding community stakeholder discussion groups, we were able to identify African Americans nationally as an underserved hospice population and determined that an initiative of this kind fit within FHPC’s mission. The chance to serve as its program coordinator was also a natural fit within the scope of my work as a community pastor.
Please tell us about FHPC’s two partners in this initiative.
Bidwell Church was first to formally partner with FHPC on this program. We are a 300-member congregation, 90 percent of whom live within the Greater North Side. The church has deep roots in the community and is over 97 years old. The leadership of the church viewed the partnership as an extension of its work. Being able to offer quality end-of-life care to our families, neighbors, and other local churches felt like a new way to reach out to those within the confines of the church as well as our community.

The North Side Christian Health Center is a long-established community service organization in the Greater North Side which offers comprehensive health care to over 5,000 patients per year, with or without health insurance. It just recently expanded its services to include dentistry and pediatric care, and added a gerontologist to its staff to address the health needs of seniors.

How did the idea for Transitions come about?
The concept came from several ideas that converged during our community stakeholder discussions.

First, local pastors expressed the need to see congregation members at the end of life in a more centralized place. Travel also proved to be difficult for the families of these congregation members who often did not have reliable forms of transportation. Next, our research showed that in our area of Allegheny County, only 5 percent of all hospice patients were African American, 3 percent less than the national average at that time. We suspected many could benefit from hospice care, but recognized that there were cultural, religious, and racial barriers that were prohibiting access. We also heard from leaders in the community who were willing to be supportive, particularly because they believed that FHPC’s services could provide a real benefit to the community.

Why did you select Transitions as the program name?
That too evolved from our stakeholder discussions. The common words used to describe care at the end of life are at
odds with the African-American culture and belief system. To African Americans, it’s not about end-of-life care or closure, but about transition.

**Had the three organizations worked together previously?**
No, the Transitions program was our first opportunity to work together. The Greater North Side community was not familiar with FHPC before the launch last year.

**Where is the Transitions program housed and what services are offered?**
The program is housed at FHPC’s Anderson Manor on the Greater North Side, with some services also provided at Bidwell Church. While the Anderson Manor site is not new to the community, up until Transitions, residents avoided it because of the historical racial practices of the former building owners. Our outreach efforts have helped to change that.

In terms of services, the Transitions program offers all of the services that FHPC provides to all patients and families, we just employ more targeted outreach to break down the barriers. We have also diversified our staff to help overcome the inherent mistrust of healthcare providers. As the Transitions coordinator, my job is to speak with families considering hospice, and design and implement educational programs to promote greater understanding and increase admissions.

**Have you specifically recruited volunteers for Transitions?**
Yes, we now have 25 volunteers working specifically for the Transitions Program. Many, but not all, are residents of the North Side and members of Bidwell Church.

We have formally trained some volunteers to help with patient care, but many help support specialized programming, such as Camp Healing Hearts for grieving children. We are now in the process of training a special group of volunteers to conduct community grief groups, which is a huge need we have discovered through our outreach.

**Can you tell us about the people you’re serving?**
We have admitted about 25 African-American patients since January of 2011 as well as three non-African Americans. Our youngest patient was in his mid-fifties and our oldest was in her early nineties. While the majority were served in the home, some received care at FHPC’s inpatient unit. Our goal, for the first four years of the program, is to serve between 60 and 65 patients.
How is the program funded?
Transitions is funded through local foundations, including grants from The Buhl Foundation, the Highmark Foundation, the McKinney Charitable Trust and The Pittsburgh Foundation. We sought support for a four-year cycle and hope to be self sufficient by establishing a patient referral stream by the end of those four years.

How are you now getting referrals?
We receive referrals from our local churches, from the North Side Christian Health Center, from doctors with established relationships with FHPC, and from the community at large. We have also formed less formal partnerships with local churches and businesses which help advertise and promote our services. These organizations include a local restaurant, a funeral home, and other children and senior service organizations located on the North Side. We are also seeing an increase in our African-American census from neighborhoods other than the North Side. Though we cannot formally count them as Transitions patients, we do know they have come to FHPC as a result of our increased outreach.

How do you integrate education about hospice and palliative care into your discussions with clients without alarming them?
It has been my experience that when speaking to families at the critical time of making a decision to access hospice care, the discussion is not alarming but comforting. Personally, it has been an empowering experience to be able to offer tangible support to families that I would not have had before the Transitions Program. Offering spiritual care at the end of life is also a help because this population draws largely on its faith in times of distress. When we deliver the compassionate care we promise, it helps to spread the word about the effectiveness of hospice and palliation when it would not have been previously considered.

It has been more difficult to speak of end-of-life issues with families, community residents, pastors, and other service agencies when there is no apparent or immediate need. The fear of death is still a prohibitive factor. The faith that helps African Americans through difficult times is also the same faith that believes healing will come in the form of cure if one prays hard enough or makes a deal with God. Facing immortality before a threat to that immortality is an alarming thing. So we try to educate residents in creative ways that are more palatable. The name “Transitions” is a way of speaking of the journey towards an after-life that includes death, but is not focused on death alone. We find it to be culturally more acceptable.

It’s been widely reported that African Americans have an inherent mistrust of the healthcare system. Are there other misperceptions that you’ve discovered that surprised you?
Mistrust of the healthcare system is grounded in historical fact. The mistrust has deepened due to insurance practices, less than compassionate providers, and the lack of transparent relationships between doctors and patients. It is difficult to trust a physician to handle your death when you have not felt cared for by medical professionals during your life. When diagnosed with a life-limiting illness, African-Americans tend to take care of loved ones at home without the benefit of training, monitoring, or knowledge and understanding of the disease process, but they do so with a lot of love and compassion. Handing your loved one over to others is seen as “giving up.”
Often, we are not invited to care for loved ones facing the end of life until all other avenues have been exhausted. Misconceptions about dying, pain management, medications and its effects, and the role of doctors in the process of dying are prevalent. There is also a lack of understanding of the Medicare and Medicaid hospice benefit. Overall, education is desperately needed.

**While still new, are you noticing a change in attitude?**
There has been a change in attitude among my congregation members. Many are participating in various programs to get more information and are seeking our advice concerning the needs of their loved ones. The community at large is also becoming more familiar with what we have to offer and word is spreading by those who have benefited from Transitions. However, it is a cultural shift that takes time and a lot of effort, but is worth the work.

**What have been some of the biggest challenges?**
It has been difficult to gather many of the pastors on the North Side to talk about end-of-life care. We have had to approach them one at a time to help explain the program. Family issues that arise around the illness of the loved one, including who is the chosen person to make the decisions about care, are difficult to navigate. Getting people to preplan arrangements is also a challenge. Again, recognizing this initiative as a cultural shift means it will take time, so we patiently work our way into that shift. I think it is also difficult dealing with the personal grief that goes along with the work that we do.

**What advice can you give to the provider interested in similar outreach?**
Every aspect of hospice, palliation and end-of-life care is new to this population. It is slow to embrace the hospice option and much education is needed about what hospice care actually entails. There is a great need to have churches and other community partners involved to help establish the benefits of hospice in the community. So know your community well and others who can be of help in spreading the word. And make sure you also have staff willing to help promote and compassionately care for the patients who will come to your organization.

---

**Are you offering a non-hospice service too?**
**And would you like your work spotlighted in NewsLine?**
**Complete our brief questionnaire.**
Health Planning & Development, LLC and Summit Business Group, LLC have created new Hospice State Profiles that include the 2010 Medicare Data.

An NHPCO Marketplace Exclusive

Each State Hospice Profile™ delivers critical information to hospice executives interested in learning how to be competitive in their state. Developed exclusively for the NHPCO Marketplace by two companies with more than 50 years of combined hospice experience, each State Hospice Profile™ provides vital county-level information for strategic planning, feasibility studies or the evolution of hospice delivery in each state.

State Hospice Profile™ Highlights

*Individual Profiles are available for all 50 States* and each Profile provides detailed characteristics of each county in that state. Easy to read and understand, full-colored charts and graphs provide information developed from an analysis of the last nine years of Medicare claims data, including the most recently available 2010 data. Each county profile contains:

- Comparative hospice penetration data;
- Summary overviews of the major hospice provider in the county;
- Analysis of location of hospice services;
- Average Length of Stay for hospice patients in each county;
- Analysis of Medicare enrollments, death rates and hospice patients;
- Market share analysis by major providers in each county;
- Trended penetration rates of hospice care in each county;
- Influence of specific factors on hospice care growth;
- Analysis of market share trends

As an added bonus, each State Hospice Profile™ also contains a National and Statewide Profile of hospice care based upon the last nine years of Medicare claims data, including the most recently available 2010 data. The National and State Profiles include such information as penetration rates, estimated Medicare Cap usage, distribution of hospice census by location of service and other important data.

State Hospice Profiles™ are individually priced based primarily upon the number of counties in each state. The Profiles are value-priced and reflective of the cost of production and the value of the information that is delivered in each Profile.

**Multi-State Discount**

Do you operate in multiple states? Purchase 5-10 states get 5% off, purchase 10-25 states get 10% and purchase 25+ states get 15% off! Representatives are standing by to assist with your multi-state order at 800/646-6460.
Thank You for Your Support

The following organizations have provided generous grant support for NHPCO’s 27th Management and Leadership Conference and related events:

AdvaCare Systems
CHAP, Inc.
Glatfelter Healthcare Practice
Home Healthcare Solutions
Hospice Action Network
Hospice Pharmacia
National HME

Home Medication
LOCK BOX

SAFETY
Secure place to store your meds

PRIVACY
Keeps your medications private

SECURITY
Secure combination lock box

Secure Lockable Containers That Safeguard Strong Prescription Drugs
Multiple Sizes • Starting at $19.99

www.lockmed.com
Attendees at NHPCO’s recent Clinical Team Conference (CTC) in San Diego had the opportunity to meet a special celebrity guest, Torrey DeVitto, who presented the Volunteers are the Foundation of Hospice Awards with Rex Allen, the vice chair of NHPCO’s National Council of Hospice and Palliative Professionals.

For those who may not be familiar with Torrey, she is an accomplished actor currently appearing in the ABC Family TV series, Pretty Little Liars, where she plays the Ivy League, over-achieving sister, Melissa Hastings, and on the CW hit-series, The Vampire Diaries, where she has a reoccurring role as Dr. Fell. She has co-starred in One Tree Hill, the series Beautiful People, and has been seen on shows such as Castle and CSI-Miami. Others may know her from movies such as The Rite with Anthony Hopkins or I’ll Always Know What You Did Last Summer. Torrey is also a talented musician who—to the delight of many NHPCO staff—plays violin on one of the tracks of Stevie Nick’s new CD.

What is perhaps most fascinating to the hospice and palliative care community, however, is Torrey’s work as a hospice volunteer. For more than four years, she has been serving as a volunteer at Mission Hospice in Glendale, California.

Last year, Torrey reached out to NHPCO to see if there might be a way she could help raise awareness of hospice care among the nation’s young people—where she has an extremely enthusiastic fan base. After discovering her
role as a volunteer, NHPCO was honored to have her join us for CTC to present our Volunteer Awards.

Torrey, who was joined by her mother, Mary DeVitto (an enthusiastic hospice supporter herself), also met with CTC participants in the exhibit hall; took part in conference activities; joined FHSSA for the “From San Diego to Africa” fundraising event (where she picked up some treasures at the silent auction); met the NHPCO board of directors; and joined leadership in a tour of San Diego Hospice and The Institute for Palliative Medicine.

NHPCO is honored to welcome Torrey as our first official NHPCO Hospice Ambassador—and we are already putting her to work! Attendees at the 27th annual Management & Leadership Conference will see her this March, where she will join us for the conference; speak with legislators on Capitol Hill; raise awareness of FHSSA activities; celebrate with us at the National Hospice Foundation Gala; and more.

NHPCO president/CEO, Don Schumacher, spent some time with Torrey and asked her questions about her involvement with end-of-life care. We hope their conversation will help you get to know our first Hospice Ambassador.

DS: When did you first get involved with hospice?

TD: I first got involved four years ago as a volunteer.

DS: Did you know much about hospice before that?

TS: No, I didn’t really know anything about hospice, but as soon as I became aware of what hospice does, something clicked and I knew this was an area that I would want to contribute to.
DS: You certainly lead a busy life in Los Angeles. Why did you get involved with volunteering?
TD: I was in a place of wanting to do something more meaningful in my life, besides my professional work. I was researching ways to volunteer on the Internet. I thought I wanted to work at a children's hospital or do something involving kids. Then, somehow, Mission Hospice popped up in my search and the more I learned about hospice, the more I wanted to be involved. I called immediately, signed up for the training session and I have been a volunteer ever since. I absolutely love being a part of this. Volunteering with hospice definitely filled the void I felt in my life at the time.

DS: We know volunteers do all sorts of things for programs. What do you do as a hospice volunteer?
TD: I count myself fortunate to work directly with patients. Basically, I do whatever each patient that I am assigned to wants or needs me to do. I do a lot of reading to my patients—which is something we both enjoy. I have helped patients and families sort through possessions to help put things in order. But most people I spend time with just want to talk. They just want to talk to someone who will listen. They find so much comfort in being able to re-tell stories from their lives and I am honored to share those precious memories with them.

DS: Looking back at what you’ve learned as a hospice volunteer, what do you think is one of the biggest misconceptions about hospice?
TD: I think one of the biggest misconceptions is that it’s scary to be with the dying, or that it would feel too morbid to be a part of it. I have found such a light in being a part of hospice, one I would have never have thought I’d discover. It’s beautiful to be a part of the circle of life. To be a part of both sides of this important journey of living—the coming in and the going out. Being a volunteer helps me appreciate things in my own life so much more.

DS: Is there a specific incident you’ve had that really made you stop and reflect on care of people at life’s end?
TD: Yes. With one patient I cared for, I was deeply affected when I realized how alone he was. He was estranged from his daughter and had no living relatives or friends. He was completely alone. Besides me and the other members of the hospice team, he had no one to talk to, no one to be there with him on his final days. That really broke my heart and that’s when I realized that THIS is the main reason I do this. No one should die alone.

DS: Can you recall a time when you had what some people call a “hospice moment”—a time when hospice made a transformative difference in the life of someone else?
TD: There was one family I worked with where it was so clear to me the difference hospice makes. If it had not been for hospice, they would not have been able to get through this hard time in their lives. It was a daughter, who had her husband and three young children, but she was taking care of her mom with no support. Hospice came and made a world of difference for all of them. The times that I or other hospice staff would be there were the times they were able to shower, feed themselves, tend to the children and do whatever else was needed. I have never felt so much appreciation as when I would come by for my hourly visits.

DS: May I ask you a question about your professional life? You’re going to be working with your husband, Paul Wesley, an actor on The Vampire Diaries, this season. Is that going to be challenging?
TD: Well we haven’t had any scenes together yet, so as of now, I still wouldn’t know! Getting to join this cast has really been such a great experience thus far.

**DS: The two of you do other worthwhile advocacy work as well. Can you tell me about it?**

TD: Paul and I are involved with the nonprofit organization, Global Roots, a grassroots children’s charity helping to improve the lives of needy children who have been orphaned or abandoned in a place of war, famine or social unrest. Global Roots is doing work in Kenya, Afghanistan, Gaza and Cambodia. I think it’s so synergistic that one of NHPCO’s affiliates, FHSSA, is supporting such important work in sub-Saharan Africa. I am hoping that if my schedule allows it, I will be taking a service trip over to Africa with Global Roots in the summer, and before or after that I would also like to visit hospices in the same area through FHSSA.
New T-Shirts Designed by Torrey
Celebrate the Spirit of Hospice

As part of her role as NHPCO’s Hospice Ambassador, Torrey has designed a special t-shirt to celebrate the spirit of hospice and help raise awareness—especially among her young following and their parents.

The short-sleeve t-shirts feature the hospice message, Comfort•Love•Respect, in a vintage cut that flatters both women and men. The message on the back reminds us that hospice is about how you live.

The t-shirts will be on sale in NHPCO’s Marketplace in the coming weeks, with all proceeds going to the National Hospice Foundation in support of NHPCO’s consumer engagement initiative, Caring Connections. Look for announcements in the weekly e-newsletter, NewsBriefs.

DS: Let me tell you how impressed I am that you are both working on behalf of important causes. It reminds me of the passion many of us hospice pioneers felt when we began this work many years ago.
TD: Thank you, Don. Hospice is something that will be a part of my life till the end.

DS: One final question. If you could share one key message about end-of-life care with Americans your own age, what would that be?
TD: That being a part of the end of life is just as beautiful as being a part of the beginning of life. To not be afraid of the unknown that hospice may seem to them. I think that, especially for my generation, death has become such a taboo subject. But there is something so uplifting when you put yourself in touch with reality and help aid someone to be as happy and comfortable as they can possibly be at the end of their journey on earth. I would want to emphasize that support and appreciation for hospice is a necessity.

DS: Torrey, thank you so much for sharing this with us. We feel incredibly fortunate to be able to work with you to help increase awareness of hospice.
TD: Of course, it’s my pleasure! I am looking forward to being with many of my hospice friends this March at the MLC.
One Cause, Two Continents
Commit to a new friend in Africa

More than 20 palliative care programs in Africa are waiting for a FHSSA partner. By committing to a partnership in Africa, you help provide compassionate care to an African community and widen your network of friends.

20 palliative care programs
with more than 670 staff and 880 volunteers,
serving 13,200 patients and 66,000 family members

Expand your community and join more than 90 US hospices who have already committed to helping meet the need for compassionate care in Africa.

Visit the FHSSA Website to Learn More.

If you’ll be attending 2012 MLC, be sure to stop by the FHSSA Exhibit Booth.
The National Center for Care at the End of Life—home to NHPCO and its three affiliate organizations—served as host site for the January meeting of the Hospice and Palliative Care Coalition.

NHPCO, together with the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, the National Palliative Care Research Center, and the National Association of Social Workers, make up the coalition that helps inform and guide discussions with policymakers and regulators on key issues affecting end-of-life care. While hospice reimbursement has been a top agenda item, the group also reviews and monitors other issues with potential impact on providers.

In addition to occasional face-to-face meetings, such as the January session at the National Center, the coalition holds monthly conference calls to strategize on issues of common concern.

Representatives from AAHPM, CAPC, HPNA, NPCRC, NASW and NHPCO at the Coalition’s March meeting at the National Center.

2011 MLC Learning Journal Wins the Gold

The Learning Journal which NHPCO produced for attendees of the Management & Leadership Conference (MLC) in April 2011 has won the gold in the All-Media Contest sponsored by the weekly online publication, Association TRENDS.

More than 400 entries were received in 22 categories, with the Learning Journal winning the top prize in the category of “Convention Program.”

The 100-page, 7 by 9 ring-bound booklet provided attendees with daily events and information organized into convenient tabbed sections. A special pull-out cover also provided floor plans of the new venue to make navigation easy. There was also plenty of space for exhibitors to share information, plus room for business cards, notes and more.

Based on the positive feedback from 2011 attendees, NHPCO plans to produce a Learning Journal for 2012 MLC. (To learn more about 2012 MLC, see the display ad on page 7 or visit the NHPCO website.)
Helping Families Cope With Grief

Making time for exercise is one of those New Year’s resolutions shared by many. But for some families who are coping with grief, there is even more reason to make time for it.

While the early days and weeks of acute grief often and understandably immobilize mourners, as the months pass, exercise can play a powerful role in helping them re-engage with life.

“Exercise gives people energy again,” says Dr. Judith Pierson, a licensed psychologist who works with people in grief. “Inertia is such a part of the grief that making your body move makes you feel better. It lifts your mood and helps you sleep better.”

Vicki Costa, LCSW, the associate director of Family Support Services at Delaware Hospice, provides five good reasons to make time for exercise—information that may be appropriate to share with some families in your care.

• **It takes you outside of your head.**
  If you look around you, at the natural setting, or the others in the gym, you see something bigger than you and your individual pain.

• **It can restore a sense of control.**
  Grief is a mystery; it moves at its own pace and it can be hard to see progress. However, exercise can give you a sense of mastery and confidence.

• **There are physical benefits.**
  Exercise releases endorphins which can increase your sense of well being.

• **It is perfect for the “instrumental” griever.**
  Instrumental grievers refer to folks who are “head-oriented” and don’t want to talk about their feelings. They are more “task-oriented” in their grief process. They want something to do.

• **It is perfect for the “intuitive” griever.**
  Intuitive grievers are “heart oriented.” They are emotionally expressive and want to talk. For them, exercise can provide a way to connect with others and have a sense of community.

Run to Remember®: More than a Fundraising Tool

By running or walking in memory of a loved one, the bereaved can create a positive legacy in addition to benefiting from the exercise. In fact, this was the very inspiration behind the National Hospice Foundation’s Run to Remember® fundraising program.

With Run to Remember, individuals register for a race of any length (e.g., 5Ks, 10Ks, half marathons, full marathons) and then register with Run to Remember. As a Run to Remember registrant, they receive a customized running shirt with the name of their loved one on the back. The funds they raise can be split 50-50 between the local hospice of their choice and the National Hospice Foundation.

To learn more about how to recruit runners and walkers at the appropriate time, contact Susan Messina at smessina@nationalhospicefoundation.org.
Samira Beckwith Receives “The Senator’s Award”

Samira Beckwith, the president/CEO of Hope Healthcare Services (based in Fort Myers, FL), has received “The Senator’s Award” for 2012, presented annually by State Senator Michael Bennett, chair of the Senate Community Affairs Committee.

According to Senator Bennett, the award is presented to “citizens in southwest Florida who have responded to the new century and to these times in unique ways.” Bennett applauded Beckwith for her working relationship with so many people in the community and her ability to provide ‘out of the box’ approaches for the benefit of patients and their care.

Beckwith has been an active member of NHPCO for many years and currently serves as treasurer and national director on the NHPCO board of directors. Among its many accolades, Hope HealthCare Services was a recipient of the nationally acclaimed Circle of Life Award for excellence and innovation in patient care.

Vilma Barrios Recognized by Schwartz Center for Compassionate Healthcare

Vilma Barrios, a home health aide at Hospice of the Good Shepherd (based in Newton, MA) was selected by the Schwartz Center for Compassionate Healthcare as the 2011 recipient of its Compassionate Caregiver Award.

Each year since 1999, the Schwartz Center for Compassionate Healthcare has honored one extraordinary Massachusetts healthcare provider and, with this award, Barrios has made history. She is the only home health aide as well as the only hospice worker to receive the award since the award’s inception.

Suncoast Hospice Accredited as Jewish Hospice Program

The Toby Weinman Jewish Hospice Program, a partnership of Suncoast Hospice and Menorah Manor of St. Petersburg, has received accreditation as a Jewish hospice program from the National Institute for Jewish Hospice. Only 55 such programs in the U.S. and Canada have earned this distinction.

Suncoast Hospice (based in Clearwater, FL) has cared for Jewish patients and their families throughout Pinellas County for many years, with the goal of offering spiritual care that honors Jewish beliefs and customs at the end of life. This accreditation confirms its commitment to meeting the needs of Jewish patients and families.
Community Hospice Names Kenny Stevenson Vice President of Compliance and Quality

Community Hospice of Northeast Florida (based in Jacksonville, FL) has promoted Kenny Stevenson from director to vice president of compliance and quality.

In his new capacity, Stevenson will provide oversight and management of compliance regulatory issues and the organization’s QAPI program, in addition to his current involvement with corporate compliance, quality, contracts and medical records.

Martha Barton Honored by Colorado State Association

Martha Barton, the president/CEO of Pikes Peak Hospice & Palliative Care (Colorado Springs, CO), has received the “President’s Award” from the Colorado Center for Hospice and Palliative Care. The award is given at the sole discretion of the Center’s board president to any person, program, or organization working inside or outside of hospice and palliative care that advances quality and access to palliative care and hospice services for all Coloradans.

Barton was recognized for her commitment and leadership in the revision of the Colorado hospice license regulations. She began that work in 2008 as chair of a state-wide committee which was charged with updating Colorado’s hospice license regulations in its entirety (the first revision since 1991).

Unity Volunteer Honored by HOPE of Wisconsin

Ann Renard, a volunteer with Unity (based in Green Bay, WI), has received the 2011 “Volunteer of the Year Award” for organizational support services from the Hospice Organization and Palliative Experts (HOPE) of Wisconsin.

A Unity volunteer for nearly 15 years, Renard has served in many areas, including office assistance, community outreach, fundraising, bereavement and patient care. In 2010 alone, she volunteered over 400 hours to support Unity’s programs.
Whistleblowing results from a failure of the ethical environment of a hospice organization to focus on its accountability for the safety and welfare of the patients and families being served. Staff of the organization believe they must take a stand for the wrongdoing of the organization, so they become “whistleblowers.” So how can a hospice organization create the “climate of compliance” to prevent it from becoming a whistleblower’s target?

Whistleblower prevention starts with the development of a set of organizational values that are referenced often by managers and are familiar to every employee, says Judi Lund Person, NHPCO’s vice president of compliance and regulatory leadership.

Here are six ways to achieve good values:

1. Develop a code of conduct that emphasizes the values guiding the organization and for which there is no compromise.

2. Build a climate of trust and accountability by establishing rules that are clear and require management to hold all staff to those expectations.

3. Form an ethics committee to develop policies and procedures that reflect the desired values.

4. Hold periodic staff education sessions on what practices your hospice regards as unethical or illegal. Emphasize the role of each employee in creating a climate of “doing the right thing.”

5. Establish a clear, published policy and procedure for all individuals to follow when they believe the present practice is irreconcilable with the organization’s values or is out of compliance with laws and regulations. Allow anonymous reporting and keep channels of communication open with the reporter of an issue.

6. Make available to staff an internal hotline or a designated compliance officer to hear concerns about possible wrong doing.
The best way to keep informed of the changes occurring in the hospice and palliative care field is to take advantage of NHPCO’s diverse range of educational offerings.

Our goal is to ensure that you and your colleagues are well-informed and better able to deliver quality end-of-life care to all members of your community.

To learn more about our upcoming national conference, our series of timely Webinars, and our E-OL distance-learning courses, just click on the tabs above.

For full details, please visit the NHPCO website: www.nhpco.org/education.
One of the winning video entries in NHPCO’s 2011 Creative Arts Contest was one submitted by Treasure Coast Hospice, based in Stuart, Florida. In this video, Adrian recounts his experience as a hospice patient and how Treasure Coast “gave him his life back.” Adrian’s Story may bring tears to your eyes, testament to its power as an outreach tool. But it is also an uplifting reminder of why we do what we do.
In August, Merikokeb Wondafresh, National Hospice and Palliative Care Organization’s Website Associate Manager traveled to Ethiopia, her home country, and had an opportunity to visit Hospice Ethiopia. She shared her story with Focus on Compassion.

This past summer, when I traveled to my home country, Ethiopia, for my sister’s wedding, I decided it was a good opportunity to visit the hospice in Addis Ababa, the capital of my country. My colleagues at FHSSA helped me make the connection with the founder of Hospice Ethiopia and it turned into an experience I will never forget.

Tsigereda Yisfawossen, picked me up to take me to her hospice. Hospice Ethiopia has a U.S. partner through FHSSA, Caris Hospice in Nashville, Tennessee.

Tsigereda is a nurse with some training in palliative care. She knew about hospice and decided to open one on her own in 2006. She’s not rich—she’s just a regular person. She rented a house in Addis Ababa and now has 11 beds for patients. Two nurses work with her to care for the patients.

Our trip to the hospice was difficult, the roads are unpaved, so she drives a 4x4 that was donated by someone in America. The roads are so bad that they often damage her car. She usually parks farther away and walks the rest of the way to the hospice, but even walking is difficult with the holes and muddy puddles.

When we arrived at the hospice she introduced us to all of her patients. When she walks in, everyone is happy to see her. They try to get up to give her a hug, if they can. Some can’t get out of bed. She hugs and kisses everyone. They think she is a miracle.

All of the current patients have cancer, children and adults. With the exception of one patient who was 65 years old, everyone was under 30. One patient is a 16-year-old with a tumor on his back that is so big he must sleep on his stomach.

continued on page 3
Palliative Care in Tanzania Continues to Grow
With Dr. Paul Mmbando As One of its Champions

A Fellowship with the San Diego Hospice’s Institute for Palliative Medicine Provides a Leader with an Opportunity to Gain Skills in Training Others.

With approximately 1.4 million people living with HIV/AIDS and an estimated 20,000 new cases of cancer diagnosed each year, the need for palliative care services in Tanzania is great. Several years ago, FHSSA, along with the Evangelical Lutheran Church of Tanzania (ELCT) and the African Palliative Care Association (APCA) sought to address this need through the Continuum of Care for People Living with HIV/AIDS in Tanzania (CHAT), under a grant from PEPFAR. While this grant came to a close last year, efforts to improve access to palliative care continue.

Tanzania’s palliative care program is still growing, thanks to champions such as Paul Mmbando, MD. As project manager for the CHAT program, Paul was instrumental in expanding the availability of morphine in his country. His unwavering commitment to improving palliative care services in Tanzania continues in his role as project manager for the palliative care unit for ELCT.

Paul was recently selected as an International Fellow with the San Diego Hospice at the Institute for Palliative Medicine, which involves traveling to the United States six times in three years. As part of his fellowship, he will participate in rotations in palliative medicine and be trained as a leader in palliative care so that he may share his knowledge and train others in Tanzania.

Focus on Compassion recently asked Paul to share his thoughts on the impact his fellowship will have on palliative care in his country.

“As one of the few palliative care trainers in Tanzania, the skills I have gained from my fellowship have helped me greatly in delivering the right information to trainees with confidence! San Diego Hospice is one place where the types of services provided meet the expected high quality of care. To me, learning from the best is a rare opportunity which will always remind me to be focused on the quality of care despite the huge difference in the available resources in our setting.”

“Most palliative care providers received their first license from Tanzania Food and Drug Authority to prescribe and use morphine last year, but the use is still being masked by the little knowledge, myths and misconceptions among the prescribers and the users. San Diego Hospice provided a wonderful opportunity for me to see the use of morphine at its very best…hence I can help other clinicians in Tanzania to improve their skills and knowledge in the use of this important drug.”
The conditions are very rough. They use two small charcoal cookstoves to make all of the meals. I wanted to buy them a new stove, but Tsigereda told me that the coal for a stove would be too expensive on an ongoing basis, so she prefers to use her cookstoves. Her greatest needs are blankets and bed sheets, they have none to spare.

The rooms are not insulated, so when it’s cold, it’s very cold, and when it’s hot, it’s very hot. They have only one hospital bed, all the rest are just regular beds.

The hospice is always full, when one patient dies, they get a new patient from referrals from two hospitals. Most of the patients don’t have a family member in Addis Ababa. They come to the government owned hospital, and are referred to Hospice Ethiopia. If they were to go home, there would be no way for them to get pain medications.

But she still worries, because there is no regulation. There are not enough doctors trained in palliative medicine. She wants badly to make policy changes to make things better, but it’s a lot for her to do—to take care of patients and do all the advocacy work.

She’s grateful for the money she gets from her FHSSA partner, Caris Healthcare, and other hospice friends in America. She applied for government funds in Ethiopia but to date has not received any government funding. She hopes to have a bigger place someday, maybe with more land she can build a bigger, better house for her patients.

Merikokeb was born and raised in Addis Ababa, Ethiopia. She came to the United States 17 years ago with her husband. They have one daughter who is 15. They have traveled back to Ethiopia, eight to 10 times, thanks to the free tickets they get through Delta, her husband’s employer.
As part of its mission to expand the availability of hospice and palliative care in sub-Saharan Africa, FHSSA, in partnership with the African Palliative Care Association (APCA), created the African Palliative Care Nursing Scholarship in 2010. The goal of the scholarship is to further the knowledge and skill of African nurses in the provision of palliative care, and will support the education and training of 11 nurses over two years.

The scholarship was made possible by a generous donation from an anonymous donor in honor of Kath Defilippi and her many achievements during her career as a nurse in hospice and palliative care in Africa.

The scholarships were given to two nurses from Cameroon, one from Malawi, one from Nigeria and two from Uganda. Ndikintum George Mbeng, head of the recently formed Cameroon Palliative Care Association, is one of those scholarship recipients. He recently shared his thoughts with us on the meaning of this opportunity.

“I cannot underestimate how much I have gained from this course in terms of skills and professional development,” he said. “I’ll use this knowledge to foster training, advocacy and mentorship in Cameroon. The knowledge gathered about policy and social development equally places me in a better position to lobby and campaign for development of a national policy towards palliative care.”

FHSSA and APCA continue to track the nurses who received the scholarship and are encouraged by the potential impact it may have on furthering palliative care in Africa. Six to seven nursing scholarships will be awarded in 2012.

To learn more about supporting this program, contact FHSSA Coordinator, Erinn Nanney at enanney@fhssa.org or (703) 647-6684.

**Nursing Scholarships Given to Six African Nurses**

**FHSSA Gets Personal Insights from One Recipient**
“Okuyamba,” A Powerful Glimpse into the Desperate Need for Palliative Care in Uganda, and the Champions Who Provide Care.

“Okuyamba” in Lugandan, the meaning of the word is “help,” making it an appropriate title for a documentary film created by The Center for Hospice Care in South Bend, Indiana with the Notre Dame University Film School, about a common mission shared by palliative care nurses in Uganda.

With exceedingly high incidence of HIV/AIDS and cancer, limited facilities for treatment, little to no access to adequate pain control, hospice or palliative care, it comes as small surprise that the adult life expectancy in Uganda is only 52 years. “Okuyamba,” is an extraordinary film that follows Rose Kiwanuka, the country’s first palliative care nurse and national coordinator for the Palliative Care Association of Uganda, as she travels throughout the country training, supporting and encouraging the nation’s 120 palliative care professionals.

The film offers viewers a glimpse into the harsh realities of living in a poverty-stricken East African country where the majority go a lifetime without seeing a doctor. As the film’s website describes, “from the training of traditional healers in the Buyija Forest to that of nurses and clinical officers at Hospice Africa Uganda, the film explains the interrelationships between traditional and western medicine as well as the manner in which they complement one another in the identification and care of dying patients.”

Catch a special viewing of Okuyamba at NHPCO’s Management and Leadership Conference. For details, see below.

FHSSA Opportunities at the MLC Conference in March

Learn more about International Partnerships, Network with Existing Partners and African Hospice Leaders

NHPCO’s 27th Management and Leadership Conference has much to offer those interested in FHSSA, international partnerships and the progress being made in furthering the availability of palliative care and hospice services in Africa.

The conference, which runs from March 27-30 at the Gaylord National Resort and Convention Center at the National Harbor in Maryland, will feature:

- The FHSSA Breakfast March 29, 7 a.m. — an opportunity to meet with other US and African hospice leaders.
  - We will celebrate the successful completion of the “One Cause, Two Continents” Campaign,
  - Announce the winner of the FHSSA Global Partnership Award,
  - Celebrate new program partners and,

- Introduce FHSSA Ambassadors
- Two Sessions focused on international efforts
  - It Takes a Village: Engaging your Local Community through International Outreach March 31, 10-11:30 a.m.
  - Four Seasons and PCAZ: Celebrating an International Partnership March 31, 11:45 a.m.-12:45 p.m.
- Special viewing of “Okuyamba,” an important documentary film about a common mission shared by a group of palliative care nurses in Uganda March 29, 3:30-4:30 p.m.

Don’t forget to visit the FHSSA booth in the Exhibit Hall! Opens March 29 at 5:30 p.m.
Please check final MLC program for locations.
“One Cause, Two Continents” Continues to Broaden its Reach
Ambassadors Help Spread the Word about the Benefits of Partnering

Partnerships have long been considered and remains one of the most valuable FHSSA programs. Partners provide technical assistance, support and friendship. Indeed, partnerships are the core of our mission. They work collaboratively to expand access to hospice and palliative care services in sub-Saharan Africa, a region where the need is great and resources are few. While there has been great success in establishing partnerships, FHSSA recognized last fall that many African hospices were still hoping for a US partner. To invigorate interest among US hospices in becoming a partner, FHSSA launched the One Cause, Two Continents Campaign.

An important component of campaign is the “FHSSA Ambassadors” program. These Ambassadors represent US partner hospices and can speak knowledgably and powerfully about the challenges and opportunities of being a partner.

One such Ambassador, Steve Taylor, spiritual care coordinator with Hospice of Washington County in Hagerstown, Maryland, shared his thoughts on what being an Ambassador means to him. “To be an ambassador of FHSSA to me is to represent a global initiative that I am passionate about: that is offering hospice and palliative care to our dear brothers and sisters in Africa. Being an ambassador with FHSSA is about communicating the needs and inspiring others to partner to make a global difference in the world by extending hospice care to those who are dying in pain and isolation. I long to foster more partnerships so that more people may be touched and comforted in their journey towards the end of life.”

The partnership campaign has been very successful, drawing new organizations interested in partnering through FHSSA. Following the first month of the campaign, FHSSA staff and Ambassadors followed up with 43 organizations to discuss their options for becoming engaged, and as a result, we now have one new US partner, bringing the total to 95 and six organizations are in the final stages of acquiring board, leadership or health system approval.

To learn more, visit www.fhssa.org or contact us at info@fhssa.org with any questions.