



Delaware Hospice's CEO and President, Susan D. Lloyd, RN, MSN, raised more than \$7,000 for NHF and her hospice. On Sunday, October 26, 2008 Susan joined 18,000 other runners at the starting line of the 33rd annual Marine Corps Marathon in Washington D.C. Susan says, "My Delaware Hospice shirt meant so much to me and I thought about our families many times during the race. Being able to run for them was so important. I know the money we raised will help. What an honor to be able to support them."

Learn How Your Hospice Can Benefit

Hospice development, marketing, and public relations specialists can attend in-person information sessions at no cost in the following cities in 2009: Atlanta, Chicago, Cincinnati, Columbus, Detroit, Orlando, San Francisco, and Washington, DC.

Come and learn how to:

1. Use RTR to raise money, expand the donor base, and reach out to the community in a new way
2. Recruit and support runners and walkers with ease
3. Have a great time and encourage people to get fit and healthy

To learn more about RTR or the specific training sessions, contact Stuart Lazarus at stuart@runtoremember.org. He is eager to help you!

Run to Remember Hospice Launch

2009 marks important changes in Run to Remember, NHF's training and fundraising program for runners/walkers dedicated to advancing the cause of hospice care locally and nationally.

In the years since Stuart Lazarus, based in Columbus, Ohio, founded the program in 2002, the focus has been on building the program's infrastructure and reaching out to the running community. The RTR program has been highly successful and now we are ready to bring it to an even wider community of supporters.

"We have perfected the program, based on input from runners/walkers. Our experience managing it has allowed it to grow larger in scale each year, explains Lazarus. "Until now runners and walkers came to us independently, seeking us out on the web or hearing about RTR through outreach at marathon Expos or from other RTR participants. Now we are focusing on promoting this program to hospices and showing them how simple it is to benefit by recruiting runners or walkers in their own communities and encouraging neophytes to tackle the challenge of a road race while raising money in honor of their loved ones."

Participants may designate 50% of their net proceeds to a local hospice of their choice; the remaining 50% benefits NHF's national programs such as the Pediatric Initiative, hospice research, and service to consumers and families through Caring Connections.

One of the biggest and best changes is that RTR participants will be able to run or walk a road race of any distance, from a 5K to a full marathon. This opens Run to Remember participation to people of all ages and abilities.

"We are confident that the changes in the program, coupled with our targeted outreach to hospice providers will yield tremendous growth in the number of runners and walkers participating and the funds raised for hospice," says Lazarus. ■

Marine Corps Marathon 2008



Photo by marathonfoto.com

National Hospice and Palliative Care Organization staffers Ronald Whisnant (left) and Brandon Nieves had never run more than 5 miles or 5 kilometers, respectively, before training for this marathon. They successfully completed all 26.2 miles and raised more than \$2,000.



The pace of handing out water can be fast and furious, but the Marines and NHF volunteers have it down to a science.



NHF and NHPCO staff members and friends joined Marines at the waterstop near the Lincoln Memorial. They worked for several hours handing water to grateful runners and cheering particularly wildly when they saw a "Run to Remember" tee shirt whiz (or walk) by. Water-slingers included (L-R) Maureen Lilly, Emil Zuberbueler, Mike Davids, John Mastrojohn, Sue Canuteson, Paula Palhus and (in front), Apryl Shaw. Other volunteers not shown include Anthony Barnes, Malcolm Kelly, and Stuart Lazarus, Run to Remember program director.



Enjoying accolades and good wishes at a pre-race reception at the NHF office were Lisa Messner, Aluko Hope, Liz Teed, Ronald Whisnant, and Brandon Nieves.

NHF Awarded a Quarter Million Dollar Grant to Support Workplace Outreach



The Jacob and Valeria Langeloth Foundation of New York has granted \$230,361 to the National Hospice Foundation for an 18-month project, *Encouraging Workplace Practices to Help Caregivers Handle Work-Life Responsibilities*.

The project will be conducted by members of the National Hospice and Palliative Care Organization's Caring Connections team which provides information and referrals to tens of thousands of patients and families each year.



How This Grant Will Help People

Research has shown that supportive work-life programs increase workforce loyalty, morale, and productivity.

This "case study" is an excerpt from our grant proposal and demonstrates how the work funded with the Langeloth Foundation grant could have an impact on one person.

Cathy has worked as an administrative assistant at her company for five years. Her colleagues describe her as dedicated and "invaluable" and they know that for the past two years, she has been helping her grandfather care for her grandmother, who has Alzheimer's disease. Cathy helps her grandfather coordinate her grandmother's care and drives him to the nursing home many evenings so he can spend time with his wife.

Cathy is responsible not only for providing emotional support to her grandmother and grandfather, but also for helping them organize all of their financial, insurance, and legal affairs in anticipation of her grandmother's death. Although she has continued to work during the past six months, she has occasionally had difficulty balancing her responsibilities to her work team with those to her grandmother and grandfather. Cathy has grown increasingly anxious under the strain and although her work performance has not slipped, she is very worried that it will.

Cathy's supervisor, George, recently completed a training sponsored by their employer that focused on how to recognize when employees might need information about or assistance with balancing caregiving and work responsibilities. George asked to meet with Cathy and then gently broached the subject of her grandparents. Cathy was relieved to have the opportunity to confide her concerns—and the nitty-gritty details

The grant enables the Caring Connections team to promote the It's About How You LIVE – At Work initiative, which helps employers support staff who are either living with a serious illness, caring for another or grieving a loss.

This is a major issue throughout the United States and NHF is proud to have found a way to help families and employers begin to tackle it with a project that can really make a difference. If you or someone you know would like to learn more about the It's About How You LIVE – At Work initiative, contact Kathy Brandt, Vice President, Professional Leadership, Consumer and Caregiver Services at kbrandt@nhpco.org or 703/837-3125. ■

of her caregiving responsibilities—to George. George was sympathetic and kind and let Cathy know that the company stood ready to help her. He set up a meeting for them with a representative from the human resources department to discuss Cathy's needs and weigh all options.

During the meeting the human resources staff member, Janet, listened carefully to Cathy as she explained the situation with her grandparents. Janet felt good about being able to help Cathy because their company had just completed all the steps in the National Hospice and Palliative Care Organization Employer's Guide to Work-Life Programs and Policies. Janet felt confident that through a combination of family sick leave and alternate work schedules, Cathy would be able to manage her work commitments while also caring for her grandparents.

Janet explained the options to Cathy and George and together they came up with a schedule that made sense. Janet also gave Cathy the toll-free phone number for the Caring Connections HelpLine and told her the HelpLine could help her locate a hospice for her grandmother as well as other local resources. Cathy also picked up several brochures that seemed like they might be helpful: "When Someone You Care About is Seriously Ill," "A Guide to Working Caregivers" and "End-of-Life Caregiving."

Cathy found the informational resources and the support of her co-workers to be very helpful. As a result of the overall response to her situation, she feels much closer to her co-workers and supervisor than she did when this process began. Now that her grandmother is close to death, she appreciates that her co-workers can fill in for her when she wants to spend some extra time with her grandmother, and that through her company's flextime policy, she can do so without compromising her position at work. ■



FHSSA Co-Hosts Successful Fundraiser: A Taste of Good Hope



Foundation
for Hospices
in Sub-Saharan Africa

In many countries in Africa there is little or no access to hospice and palliative care, including adequate pain medication. Desperate situations of suffering,

stigma, poverty, and isolation for the terminally ill and their families are common. The situation is particularly acute for women and children.

The Foundation for Hospices in Sub-Saharan Africa (FHSSA) exists to help alleviate this suffering and NHF helps in many ways. Recently, we were able to help by obtaining several hotel stays as items for a silent auction that took place on the evening of October 25, 2008.

That night, FHSSA and The Hospice Foundation of the Florida

Suncoast hosted a South African *jabula* to raise awareness about the HIV/AIDS pandemic in Africa. A *jabula* is an annual fundraiser filled with sounds of South African music. This one was aptly named, "A Taste of Good Hope" in honor of The Hospice of the Florida Suncoast's longstanding relationships with their partner, The Hospice Association of Witswatersrand in Soweto, South Africa.

The event was held on the beautiful 23-acre grounds of The Hospice of the Florida Suncoast in Tampa. Attendees sampled delicacies and delights from local restaurants and wines from South Africa. The event raised \$32,000. All the proceeds directly benefit those who manage serious illness everyday while continuing to struggle with serious economic hardship. Our thanks to the Board and Staff of FHSSA and all our friends at Suncoast for their ongoing support! ■

Pediatric Standards: Why They Matter

Despite amazing progress in medicine and technology, many seriously ill children suffer from pain and other distressing symptoms. Since they are not always able to express it in words, if they are very small or very ill, only cries, silence, or even an arched back may reveal the depths of their pain.

Sometimes, children pretend that they are not in pain, because to admit pain is often to lose the opportunity to do something fun, like a family outing, or normal, like attend school. Knowing how to read the pain signals of infants through adolescents—and how to treat it appropriately—is as much of an art as a science.

There can be challenges to treating a child's pain; sometimes even parents are a barrier. Occasionally parents may have conflicts about pain medication, despite their child's obvious distress, due to their own fears or beliefs. The hospice or palliative care team has to work carefully with these families to ensure that the child's needs are met without alienating the parents.

Hospice and palliative care providers working with children will have an important new resource in early 2009 when the first national set of Standards of Practice for Pediatric Hospice and Palliative Care Programs are released. These groundbreaking standards were created by NHPCO's Children's Project on Palliative/Hospices Services (ChiPPS). The development of the standards was made possible through the generous gifts made by James R. Borynack, Brickson Diamond, Rita Stein, Judith C. Korn, Buddy and Nava Korn, and The Mary and Emanuel Rosenfeld Foundation.

The start of 2009 will mark the 11th year for the Children's Project on Hospice and Palliative Care Services (ChiPPS). This group created the Standards of Practice for Pediatric Hospice and Palliative Care Programs.



These new standards will give providers clear guidance for providing high quality end-of-life care for children and their families. Pain management is addressed under the "Clinical Excellence & Safety" standards and includes many specific sub-sections to guide providers in designing programs and providing state-of-the-art care. Here is one practice example that will be part of the Standards: A 15-year-old refuses to continue palliative radiation because getting out of bed in the morning causes him too much pain. His hospice or palliative care nurse suggest starting his "breakthrough" dosing (to control pain) before even getting out of bed. He begins this routine, and is able to finish the radiation course which decreases the size of his tumor and his pain. With the response he is able to stop his continuous intravenous medication temporarily, go back on oral pain medication, and return to school to finish the school year.

For more information about the pediatric standards of practice and other resources, visit www.nationalhospicefoundation.org/pediatrics. ■

National Center for Care at the End of Life



A conference room large enough for staff (and boards) to meet is one of the many features of our new home at the National Center for Care at the End of Life, which houses NHF, the National Hospice and Palliative Care Organization, the Foundation for Hospices in Sub-Saharan Africa, and the Alliance for Care at the End of Life. Prior to the move, all large meetings had to be held off-site, at additional expense. Here, NHPCO's Kathy Brandt gives the entire team an update on Caring Connections, NHPCO's consumer education program, which NHF supports with foundation, corporate, and individual gifts.



NHF is deeply invested in helping FHSSA achieve its mission of meeting the tremendous need in sub-Saharan Africa for the caring and comfort that palliative care can bring to the seriously ill, dying, and their families. The NHF and FHSSA teams, meeting here in the African-themed President's Board Room, work closely together on a variety of projects.



This inviting pathway leads directly to the National Center for Care at the End of Life at 1731 King Street, Alexandria, Virginia.



The reception area greeting visitors to NHF, NHPCO, FHSSA, and the Alliance passes some of the new meeting spaces that include an art gallery currently featuring original paintings by Zachary Morfogen, NHF Foundation Chair Emeritus. On the second floor is a cozy library that doubles as a small conference room.



2009 National Hospice Foundation Gala
Bricks and Diamonds
Setting a Foundation for the Future

Friday, April 24, 2009
Omni Shoreham Hotel
Washington, DC

In addition to NHF's annual awards, Bricks & Diamonds will feature a silent auction showcasing estate, gently used, and one-of-a-kind jewelry. We need your help to make it a success! Please consider donating a special piece to this unique auction.

To learn more about the gala or to contribute to the auction, contact Katrina Lucas at 703/647-1574, or email klucas@nationalhospicefoundation.org. ■

Consider a Planned Gift

You can ensure the future of the National Hospice Foundation's work while meeting personal estate and financial goals by making a planned gift. Please consult with your estate planner, attorney, or tax advisor for additional guidance on making a planned gift. For the full range of planned giving options offered by NHF, consult www.nationalhospicefoundation.org (under the "Get Involved" tab) or contact Maureen T. Lilly, Director, Planned Giving and Donor Stewardship at 703/647-5173 or mlilly@nationalhospicefoundation.org ■

Learn more about NHF at
www.nationalhospicefoundation.org

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