

# Giving Matters A newsletter of the National Hospice Foundation

#### WINTER 2013



Browse Campaigns



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## NHPCO Affiliate, FHSSA, Launches into Crowdfunding

New Fundraising Tool Encourages Individuals to Contribute and Raise Awareness About Projects in Africa

FHSSA has created a crowdfunding platform as a new means to raise awareness and support for its work. Through FHSSA's innovative Partnership Program, more than 90 hospices in the U.S. are partnering with palliative care organizations in Africa to provide support in 14 African countries where pain all too often goes untreated.

Support between partners comes through the provision of necessary supplies, sharing expertise and best practices, fundraising efforts in the U.S., and perhaps most importantly, relationship building. The new crowdfunding platform is an exciting new tool that will help expand outreach to potential donors for FHSSA and its U.S. and African partners. Sometimes referred to as "social fundraising," crowdfunding describes an effort by individuals who network and pool their resources to support a cause or individual project. The goal of FHSSA's first crowdfunding campaign, launched in December, is to raise \$10,000 for FHSSA's Conquering Pain project. There will be additional FHSSA-focused campaigns in the future.

"Even one dollar can have an impact when you're working to make a profound difference for people in Africa who are struggling with illness and pain," said John Mastrojohn, executive director of FHSSA. "Our crowdfunding site is a great way to donate, share among friends and family and to know specifically how your contribution will be used to make a difference."

FHSSA Partners can create their own, custom crowdfunding campaign pages and connect with their community, encouraging people to get involved and support their work in Africa. In addition, donors can visit FHSSA's crowdfunding site, choose the project and location in Africa that is important to them, and donate any amount.

Visit <u>http://crowdfunding.fhssa.org</u> to learn more about this new tool and to see the current projects using crowdfunding.

## The National Center for Care at the End of Life is Home to the New Mary J. Labyak Institute for Innovation

### Institute Focuses on Making a Powerful Difference in End-of-Life Care Through Education, Leadership, and Outreach

As part of its mission to lead and mobilize social change for improved care at the end of life, the National Hospice and Palliative Care Organization has created the Mary J. Labyak Institute for Innovation. The Institute, which is named after the late hospice pioneer, Mary J. Labyak, is designed to continue her legacy of listening, learning and innovating.

Labyak, who died in February 2012, was one of the most widely-recognized innovators working on behalf of hospice and palliative care in the U.S. The Institute bearing her name continues her work by developing and promoting new strategies to ensure the best possible care for patients and families—and by always keeping the needs of patients and families at the center of hospice care.

"More than 40 years ago, innovators such as Mary took the core of an idea and built the foundation upon which today's hospice and palliative care providers serve millions of patients and families each year," said J. Donald Schumacher, president and CEO of NHPCO. "With the creation of this



# to make a gift tomorrow.

Learn about the opportunities to give and save-meeting your financial goals and maximizing your charitable intentions through gift planning with the National Hospice Foundation.

www.nationalhospicefoundation.org/give



National Hospice Foundation

Institute, we take a giant step forward in ensuring that the innovation that changed the health care landscape so many years ago continues to improve the quality of health care delivered today."

The Institute is comprised of eight Centers that work collaboratively to advance the care continuum through education, leadership, and resource dissemination. Each Center will determine gaps in practice, identify resources, and develop and disseminate tools to deliver the best possible care to patients and families. The eight Centers are:

- Children's Hospice and Palliative Care
- Consumer and Caregiver Engagement
- Ethical Practice
- Expanding the Continuum
- Grief and Bereavement
- Leadership Development
- Spiritual Care
- Veterans' Care

Work at the Institute is well underway. The recently published Pediatric Concurrent Care Continuum Briefing is the first in a series of papers to be made available on the NHPCO website. In late January 2013, the Institute will hold a three-day event in Florida, "Creating the Hospice and Palliative Care Continuum: A Futuring Forum," designed to stimulate the design of new programs to care for people earlier in their illness. In April of 2013, the Institute will host an Innovation Intensive in conjunction with the Management and Leadership Conference, headlined by former CMS administrator Don Berwick.

The Institute was started with funding from Mary Labyak's estate and memorial gifts in her honor, as well as an investment by NHPCO. NHF is engaged in fundraising efforts to provide additional support for the Institute and its work.

For more information on the Mary J. Labyak Institute for Innovation, visit nhpco.org/Innovation, or contact Executive Director Kathy Brandt at kbrandt@nhpco.org.

## ADD SPECIAL MEANING **TO YOUR** GIFTS

Show the ones you love that you really care. Each time you make a purchase from one of these vendors, they will donate \$10 to the National Hospice Foundation.

**ProFlowers**<sup>®</sup>



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### **CHERRY MOON FARMS®**



Or if gift cards are what you're looking for, TisBest Charity Gift Cards allow the recipient to make a donation to one of 250 national charities, including NHF!

www.nationalhospicefoundation.org/ TisBest

Remember also to purchase your greeting cards through Cards for Causes, and 20% of your purchase will go to The National Hospice Foundation! www.cardsforcauses. com. They offer cards for every occasion!

These programs will run through 2012 so include NHF for all holidays to add special meaning to your gift purchases.

www.nationalhospicefoundation.org/Shop





Jeannie Forrest

### Why Giving Matters to Me

#### A Monthly Donor Shares Why She Chooses to Give to Hospice

One way to support NHF and give to hospice is through monthly donations. Even a small amount each month makes a difference in the lives of those facing the end of life. Jeannie Forrest is one such donor who shared her reasons for giving.

Hospice is important to me for a couple of personally philosophic reasons and for simple pragmatic reasons.

On the personal level: I've had experience with close friends using hospice services and have been consistently dazzled with the level of kindness and professionalism of the hospice volunteers. Hospice services allowed for their gentle, serene passing surrounded by family and friends, rather than a clinically invasive, cold and impersonal experience. Collectively, we hate to talk about death and about the end of life because it taps into a profound and universal fear of the unknown. But ignoring it leaves us lonely and

scared and unable to exercise our potential for a loving peace. Counter-intuitively, the stuff we choose to ignore is precisely the stuff that makes us the most anxious; supporting hospice is one of the ways I pay attention.

On the practical level: As we stretch the limits of technology to extend life with medical overtreatment and futile care, we're propping up a broken system. Sometimes administering medical care at the end of life actually contributes to suffering; hospice is a lovely and sensible alternative to that kind of systemic abuse. What is astonishing about medical doctors and their end of life treatment is not how much they get, but how little. Maybe we should be taking a lesson, eh?

Hospice assures a better quality of life, right to the end of life.

Jeannie Forrest is Vice Dean of New York University School of Law.

To learn more about monthly giving, contact Heather Slack-Ratiu at <u>hslackratiu@nationalhospicefoundation.org</u> or (703) 837-3155. To set up a monthly donation, visit: <u>www.nationalhospicefoundation.org/donate</u>.



### **NHPCO's Regulatory Team Helps Providers**

#### By Jennifer Kennedy, MA, BSN, CHC, LNC, Director, Regulatory & Compliance

It is a regulatory jungle out there, even for hospice providers! Ask any hospice professional and they will say that the most important thing they do every day is ensure that patients and their families receive high-quality, compassionate care. However, in order to be a hospice provider, a hospice must be

licensed by their state and certified by the Centers for Medicare and Medicaid Services (CMS) if they choose to receive Medicare reimbursement.

State regulators and CMS consistently review and update regulations and guidance that affect how hospice providers are required to operate their hospice and care for their patients. The passage of the Patient Protection and Affordable Care Act in 2010 requires a hospice physician or nurse practitioner to perform a "face-to-face encounter" with all hospice patients after they have been in hospice care for two benefit periods. Hospices also are required to measure and submit of hospice quality measures to Medicare as proof of quality hospice care.

The last several years have brought huge changes in the hospice industry. With all of the new requirements, hospice providers have had

to adjust their operations and staffing significantly to be compliant in order to remain Medicare certified and receive crucial reimbursement.

Regulations from CMS are often complicated to understand for the average hospice provider. Enter, NHPCO's Regulatory Team! We monitor all communication from CMS and other federal agencies and translate the requirement for hospice providers into understandable language. We provide hospices with tools, resources, and education based on regulatory requirements to help them become and remain compliant. NHPCO has developed numerous tip sheets, education programs, process algorithms, and webpage information so that providers can locate specific topics and instantly understand the requirement. NHPCO's Regulatory Assistance is also available to NHPCO members when they have a regulatory, compliance or clinical question. NHPCO answered approximately 4,500 questions from hospice providers in 2012, in addition to numerous calls from consumers.

Helping hospice providers to become and remain compliant and provide high quality care is a high priority for the NHPCO regulatory team. We are there for hospice providers so that they can be there for their patients and families.

Contributions to NHF help fund the work of the Regulatory Team. To help support this work and other projects, visit www.nationalhospicefoundation.org/donate

## mumms <sup>®</sup> Software and AtRisk Registry<sup>™</sup> Lend Support to Hospice By Naming a Space at the National Center for Care at the End of Life

#### Contributions Push the Campaign for the National Center to \$3.8 million

Support from individuals, corporations, and foundations have helped the campaign to raise funds for the National Center for Care at the End of Life closer to our goal of raising \$10 million by 2015. One of the many ways to give to the campaign is through NHF's naming opportunities which allow donors to select a space within the National Center to designate with their name or in honor of someone by making a contribution.

mumms Software and AtRisk Registry recently contributed to the National Center through a naming opportunity. mumms is a comprehensive mobile software system that fully integrates hospice and palliative care programs. The system is designed to automate and streamline the coordinated care required for hospice programs. The AtRisk Registry, an offspring of mumms, was created in response to Hurricane Katrina and its effect on end-of-life care throughout the Gulf Coast. The AtRisk Registry is a secure, web-based patient tracking system used by Gulf state governments and hospices, and is available to all state hospice organizations.

"During the 21st century the National Center is poised to become the nexus for educating and cultivating future hospice caregivers," said Leo Radosta, President. "Together the staff at mumms and the AtRisk Registry have demonstrated an unwavering two-and-a half decade long history of professional and personal investment in supporting and expanding hospice care. We'd like to be remembered for the value of our work as it expanded beyond the caregiver's reach."

To learn more about the National Center for Care at the End of Life and ways to support our campaign, visit: www.nationalhospicefoundation.org.

IN CONJUNCTION WITH NHPCO'S 28TH MANAGEMENT AND LEADERSHIP CONFERENCE

Save the Date

NATIONAL HOSPICE

#### FRIDAY, APRIL 26, 2013 Gaylord National Resort & Convention Center National Harbor, Maryland

6:30 pm Cocktails and Silent Auction 7:30 pm Dinner, Awards, Live Auction and Dancing

Gala sponsorships are available with priority table placement for commitments received before January 18, 2013. To learn more, contact NHF at (877) 470-6472, or visit www.nationalhospicefoundation.org/2013gala

## Plans for the National Hospice Foundation's Annual Gala Are Underway

#### Join Us As We Pay Tribute to Our Pediatric Patients

The 2013 Gala will embrace those at the center of our care—the patients and families we serve. This year, we pay special tribute to the youngest , our pediatric patients. With actress Melissa Gilbert as our Honorary Chair, we will honor these heroic patients and those who love and care for them.

Our program will feature the Center for Children's Hospice and Palliative Care, a center of NHPCO's Mary J. Labyak Institute for Innovation. Through this center, NHPCO is committed to making the best-known practices in pediatric hospice and palliative care more available to care providers. Working in collaboration with the Children's Project on Palliative/Hospice Services (ChiPPS), NHPCO focuses on raising awareness of how children's needs are different from those of adults and educating hospice providers about how to best care for them and their families.

We hope you will join us for this fabulous celebration. For more information, we invite you to visit www.nationalhospicefoundation. org/2013gala.

## An Evening of Gratitude

## NHF to Recognize Sponsors and High-Level Donors

Special guests and donors will board the Odyssey for an Evening of Gratitude on Wednesday, April 24, 2013. An Evening of Gratitude thanks all sponsors and donors who have supported NHF and FHSSA in the past year. We welcome members of The Legacy Society, high-level donors and contributors to the many programs and campaigns, and event sponsors.

# Generous Donation to NHF Uncovers a Unique and Exciting Life Story

#### A Former Spy Gives to Hospice in Her Will

One of the joys of working at NHF is learning about our donors and what motivates them to give to hospice. We recently learned about L. Evans, who gave to NHF through her estate. Evans' history was so unique we wanted to share it here.

We first learned of Evans when we were contacted by her attorney with the news that in her will, she designated the National Hospice Foundation as one of three charities to receive funds from her estate. In total, her contribution to NHF will be over \$100,000. According to her attorney, Evans was an extremely intelligent, generous, and very private individual. She was cared for by hospice at the end of her life, and had designated hospice in her will three to four years before her death. Her attorney shared a bit about her background and the exciting life she led.

Evans was born in 1921 in Maine. After losing her mother at an early age, she was raised by her father who worked in the lumber and forestry business. She was very gifted in linguistics and eventually became fluent in French, German, Spanish, and Italian. She was recruited following college by the US Naval Intelligence, the division which later became the Central Intelligence Agency. She lived most of her life overseas in Europe during WWII, the Korean conflict and the "Cold War." She loved the life and times in Paris the most and returned there nearly every summer to spend time with friends attending art museums, cultural events, and playing golf. She even related stories of working undercover, attending the opera and brushing shoulders with the likes of the King of Spain. And, like any good spy, she even passed microfiche at parties!

Evans never married and had no children. She died in September 2011 at the age of 89. Her generosity will touch the lives of many.

If you would like to share your hospice story with us, please visit our website at: <u>www.nationalhospicefoundation.org/shareyourstory</u>. To learn more about how you can create your legacy, contact Heather Slack-Ratiu at <u>hslackratiu@nationalhospicefoundation.org</u> or (703) 837-3155.

## He Had an Idea and Ran With it

#### Stuart Lazarus Retires from Run to Remember 10 Years after Founding It

Lots of people have good ideas, but very few actually see them through to fruition. Stuart Lazarus is one of the few. As a former NHF board chair, he was already deeply committed to hospice care, having seen the difference it made in his own mother's life. Franny Lazarus, of Columbus, Ohio entered hospice care in 1982, when, as Stuart explains, "There was only one program in the city and it was small. So, as she was in most things, Mom was a trailblazer, trying something relatively new but which held great promise both for her and our community."

In 2002, Stuart hatched a plan that combined his passion for running with his interest in hospice. He named it "Run to Remember" and trademarked the name. In the next two years, with volunteer help, he obtained a logo, created a website (www.runtoremember.org) and a brochure, and recruited the first people to join him. In 2005, he brought the idea to the NHF board and it was adopted as a fundraising program.

More than \$800,000 has been raised for hospice care through Stuart's brainchild, which he has lovingly tended for a

decade. Having worked closely with NHF staff the last few years, he was ready to turn the entire program over to NHF ownership, which happened officially on December 31, 2012.

NHF Executive Director John Mastrojohn says, "We are deeply grateful to Stuart for having such a wonderful idea and working with great commitment to grow the program. It has helped hospices across the country as well as NHF. We urge hospices to consider learning more about the program and how it can help them raise funds."

Run to Remember is "any race at any pace" so that runners—or walkers—can select any race in the country and designate it as their "Run to Remember." It could be a local 5K or a marathon/ultramarathon in an exotic location—and any race in between.





Stuart Lazarus



#### National Hospice Foundation

Committed to compassionate care at the end of life

1731 King Street, Alexandria, Virginia 22314 Ph: 703-516-4928 or 877-470-6472 Fax: 703-837-1233

info@nationalhospicefoundation.org

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## Did Hospice Help Someone You Love? Dedicate your Next Race to them.

- Run in Their Memory
- Raise Funds for Hospice, Locally and Nationally

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