

The Marla Ceely Lamb Fund

Thanks once again to the dedication and work of Marla's family and friends and to the generosity of the people of the community, the Marla Ceely Lamb Fund continues to thrive and served over 100 people this year. This year, the annual Mother's Day Dinner and Auction, the Walk for Transportation, this year in memory of Kelly West, a thoughtful benefit by the NHS Girls' Basketball Team, a nice donation from the American Cancer Society, and the

many memorial gifts received have all kept this valuable fund supported. So many people express their appreciation for how much the fund benefits the community and, and we are very grateful to all who've contributed. We also continue to express sincere thanks to Cape Air/Nantucket Airlines, Island Airlines, the Hyline, and Marine Lumber, for all of their assistance with the transportation needs of our patients.

Upcoming & Ongoing...

Tree of Remembrance Service: Sunday, November 22nd at 4:00 PM in the Gazebo Garden of the Jared Coffin House
Coping with Cancer Support Group: every other Monday, 1-2:30 PM, for persons with cancer and those who love them
"Time Out" for Caregivers: every 2nd and 4th Tuesday of the month, 1:00-2:30 PM

Tapestries - our program for grieving children and their families

Through our Tapestries Program, education is provided to families of children impacted by grief from the death of someone they love. When enough families are interested to form a group, bi-weekly sessions are provided to help children process their grief in a very gentle way. We also have a wonderful library of resources for both parents and children that many have found helpful. For more information, please contact our office. As always, these services are offered free of charge.

Support for Family Caregivers

Through our Caregivers' Connections Program, family caregivers of persons with any long term illness or disability can access education, support, and practical assistance from our staff, in their efforts to provide care for their loved one as well as remembering to take care of themselves. Services include:

- **Coaching for Caregivers** - one on one consultations with our Nurse Practitioner on any aspect of care;

- **Time Out** - stress reduction education and/or counseling, in the home or office, which may include talking, learning relaxation techniques, yoga, etc. Thai Shiatsu massage is also available;
- **Volunteers** - can provide 1 - 2 hour/week for respite breaks for caregivers, or can help with errands, transportation, etc.;
- **Lending Library** of caregiver-related topics.

All our services are free of charge! For more information or an appointment, please call our Office at 508-825-8325.

Hands Across the Water

Our "twin" hospice in Cradock, South Africa, continues to do amazing work with limited resources. In their last report to us, they noted that they currently have 400 clients with HIV disease, 39 patients with cancer, and 78 children who attend their day care program for orphans. Over the past few years, we've designated one item per year in our Annual Dreamcatcher Auction to be earmarked for Cradock. This year we sent \$4000 through the Foundation for Hospices in Sub-saharan Africa to help Cradock, money which will be used to help support their orphan program. If anyone is interested in supporting this cause, please let us know or visit at the FHSSA website at www.fhssa.org.

Hospice Care of Nantucket Foundation

Board of Trustees: Geoffrey Silva, President...Betsy Brown, 1st Vice President...Mary Smith, 2nd Vice President... Judy Waters, Secretary...Eugene Collatz, Treasurer...Robert Barmen...Richard Beaudette...Gussie Beaugrand...Nancy Chase... Michael Getter...Peggy Gifford... Louise Hourihan... John Penrose... Patricia Rottmeier... Jennifer Shepherd...Richard Wolfe
Hospice Care of Nantucket Foundation is a not-for-profit tax exempt public charity.

A Partnership in Caring

Funded primarily by the Hospice Care of Nantucket Foundation, the palliative & supportive care program is operated as a department of the Nantucket Cottage Hospital, which is an affiliate of Massachusetts General Hospital, and a member of Partners HealthCare, Inc. Palliative & Supportive Care of Nantucket is a specialized health care program, dedicated to providing excellent physical, psychological, social, and spiritual care to persons with life-threatening illness and their families.



Palliative & Supportive Care Currents

Vol. 17, No. 2

Fall 2009

Program Director's Annual Report

by Charlene Thurston, R.N., A.N.P.

It's been quite a year! At about this time last year, we were in the midst of deliberating over whether to work towards becoming a Medicare-certified hospice program or to change our name from hospice and work towards expanding our services for persons in the early phases of life-threatening illness. As most of you know by now, we chose the latter route and have, thus far, been surprisingly gratified by the results.

Most of the year has been spent on revising our program offerings and revising our policies and informational brochures accordingly, while continuing to offer all of our patient care services. While our end-of-life procedures remain essentially unchanged, expanding services for the early phases of illness has involved much exploration of state-of-the-art care, including what's being offered around the country in non-hospice programs - often called "supportive care" programs. While many hospices have added some palliative care services to their programs in order to care for patients with a longer life-expectancy than six months who are continuing to pursue treatment, these services are usually fairly limited. Our goal was to become much broader in scope than this, and to offer our full range of services to patients who are even hoping to fully recover.

What we are developing is a readily identifiable program, which will encompass the entire continuum of life-threatening illness, from the time of diagnosis through cure, or, if cure is not possible, through advancing illness, death, and bereavement and support for their families. Patients in the earlier phases of illness are faced with the shock of hearing a serious diagnosis and, often, prognosis, and are faced with many major decisions, while, at the same time, feeling overwhelmed. They and their families are often destabilized as they experience grief and turmoil, and often employment and financial struggles, while they try desperately to find the best treatment options available and deal with the side effects and consequences of such treatments. If all goes well, the patient may be cured; if the disease is not curable, the patient and family must deal with the eventual terminality of the illness. In either case, their lives are disrupted for many, many months, and, often, years, and they usually don't have a readily available program of services to help them through this experience. This represents a gap in services for a very vulnerable patient population in our overall healthcare system, a gap which we're now trying to fill for patients in our community.

Before now, patients would go from physician to physician, and treatment to treatment, but there was no comprehensive support program in place to help them navigate through the system or to help them deal with the psycho-socio-spiritual effects of what they and their families were experiencing. While we had attempted to reach out to support this group of patients while being named "hospice," we found that patients who were pursuing cure or life-prolonging treatments were very reluctant to access services from a program named "hospice" with its connotation of "giving up and dying."

Our plan now is to serve as this comprehensive support program by offering individualized assessment, assistance with symptom management, education, basic counseling, stress reduction, support, and

Tree of Remembrance Service

We hope you'll join us for this annual memorial service, which will be held this year on Sunday, November 22nd, at 4PM, once again in the gazebo garden of the Jared Coffin House. At the start of the holiday season, the brief but moving ceremony, is a special and peaceful way to remember and honor loved ones who have died. Scallop shell ornaments are made available to write names of those we wish to memorialize and then placed on the tree. (Other weather-proof personalized ornaments are welcome as well.) Participants may bring readings. All members of the community are welcome to participate in this very special event. After the service we will gather for refreshments upstairs in the Brotherhood.

referrals, when needed. Services are offered through private consultations and group support with the appropriate member(s) of our staff, which includes a nurse practitioner, palliative care counselor, social worker, and volunteers.

It's been interesting to see the increase in consultations and admissions to our program since beginning to publicize the changes we're making. In compiling our patient activity statistics for the 12 months, we've seen a dramatic increase in the number of earlier phase patients who've accessed our services, especially since early '09, the time at which the decision was made to change our name. While the number of "comprehensive care patients" (formerly called "hospice patients"), the number of community grief clients, and the number of caregiver clients remained about the same as the prior year, the number of palliative & supportive clients with earlier phase illness increased from 11 last year, to 37 this year (336% increase), with the number of private sessions for this group increasing from 63 last year to 150 (240% increase) this year! Moreover, most of the increases were seen after 1/09. This increase confirmed our belief that many more patients could benefit from our services than were accessing them, probably due to the connotation of death and dying with the name "hospice." We've also found that health care practitioners from other departments and agencies are more comfortable referring patients for our supportive services than they were when called "hospice."

While most of our efforts over the past year have been concentrated in converting the program, we've, of course, continued to provide our usual end-of-life care. Over the past year, 59 people have died in Nantucket from any cause, including sudden deaths, accidents, etc., and we have provided care for 25 of them (43%), a rate which is 4% higher than the national average for hospices. Over the past several months, we've also worked diligently, along with other concerned citizens, to try to rescue the Adult Community Day Center from being cut from the services of the town.

We were thankful that a sense of the meeting vote at the recent Special Town Meeting demonstrated overwhelming support that the

The Dreamcatcher Dinner & Auction

Our 16th annual Dreamcatcher Dinner and Auction was held in June under the tent at Galley Beach and once again dreams came true for our program as well as the successful bidders. The live music from the band Kahootz created a festive mood and party atmosphere, and everyone had a great time.

Many, many thanks go to all of the "Dreamcatcher" volunteers from the community as well as our Trustees who helped to make this a tremendous evening for all. We wholeheartedly thank the event Underwriters and Sponsors whose loyal support is so important to our financial success.

Again this year a table was sponsored and reserved for our dedicated Hospice volunteers, and we thank Trustee, Mary Smith and her husband, Jeff, for making this year's Angel Table possible.

Once again we are grateful to the several island landscape companies and the students of the Nantucket

New School who will be planting hundreds of daffodil bulbs along the Milestone Road again this fall in honor of Hospice. Yellow "daffodil cards", each with a value of \$250, were available to all who attended the auction and it was heartwarming to watch the sea of yellow cards when Raphael introduced this auction item which raised \$10,250 for Palliative & Supportive Care.

Rafael's signature auction item, the memorial sunset, gave donors the opportunity to honor and memorialize loved ones and friends adding an additional \$20,000 to our program.

For the 5th year, we set aside one of our live auction offerings and dedicated the income to our South African partnership, which through recent donations has provided renovation of the Cradock Hospice building and medical supplies from Direct Relief.

Again we thank the Nantucket community, not only those who attend but also all of the individuals and local businesses who year after year generously donate many of our wonderful auction items and in-kind services in support of our main fundraising event. The evening was superb and the auction was a great success.

Board Transitions

This year, we express our sincere gratitude to Sandy Knox-Johnston and Michael Varbalow, our outgoing board members who each served for six year terms. We are deeply grateful for Sandy's efforts, particularly for her work in helping to make our Dreamcatcher Auction what it is today, first as a volunteer of several years, then as a board member. We are grateful for her enthusiasm and hard work in bringing Direct Relief International together with the Foundation for Hospices in Sub-

saharan Africa, a relationship which has resulted in bringing much needed supplies to many African hospices. And to Michael, we extend our thanks for his commitment and leadership, particularly his contributions regarding appropriate legal affairs of the organization, and for sharing his experiences from working on boards of other Foundations. Michael is a life-long volunteer and a devoted member of the Nantucket community who serves on many boards and councils and we are fortunate that Michael shared his time and experience with us. Welcome to our two new board

members, John Penrose and Richard Beaudette. John Penrose is a former CEO of several healthcare companies and is now "somewhat retired" with a passionate commitment to serving the Nantucket community. Richard P. Beaudette, having received his JD from Northeastern University in 2003, is currently a partner with Vaughan, Dale, Hunter, Stetina & Beaudette PC here on Nantucket. We look forward to benefitting from their experience and to the contributions they will bring to our foundation.

Support for Veterans

Veterans who are facing life-threatening illness often have experiences that are unique to their military service, particularly if they have been involved in combat. In an effort to help veterans in their home communities, the Hospice and Palliative Care Federation of Massachusetts formed a collaboration with the V.A. Healthcare System to

ensure that the needs of vets during serious illness, dying, and bereavement could be met, in an informed and sensitive manner, by hospice and palliative care practitioners who have been educated about their unique needs. We, at Palliative and Supportive Care of Nantucket, have joined with several other hospices across the state to provide this service to veterans and

their families in our community. We also own a copy of the award-winning DVD, "Wounded Warriors" in which nationally-recognized expert and VA nurse, Deborah Grassman, explores the issues veterans confront at life's end and offers strategies to provide them with compassion, dignity, and respect. Please don't hesitate to call on us for further information.

DID YOU KNOW... We've change the name of our program from Hospice Care of Nantucket to Palliative & Supportive Care of Nantucket! The Foundation's name will also change in December to Palliative & Supportive Care of Nantucket Foundation.

Director's Report *continued from page 1*

program be continued. We'll continue to work to try to maintain this very important service, a service which we helped create in 1991.

Our volunteers have provided a total of approximately 400 hours to support patients and caregivers over this period. Most volunteer assistance has been utilized in providing respite to caregivers through our caregiver support program.

Other activities we've been involved with have included continuing to assist Cradock Hospice in South Africa, continuing to provide education on advance directives, and continuing to provide professional development opportunities, both for our own department's staff and for staff of other departments and agencies. Over the past year, I've attended a Cancer Guides Workshop (complementary and alternative therapies in cancer care), and will be attending Harvard Medical School's Palliative Care Conference in October, and our Palliative Care Counselor is attending 2 workshops to further develop her skills in Thai Shiatsu Massage, a type of bodywork that we've been offering to decrease stress and enhance well-being. We've recently sponsored 14 participants' attendance at the Alzheimer's Services "Seminar by the Sea," a conference which focused on the use of compassionate touch to help calm and soothe patients. The attendees included our Volunteer Coordinator, 3 of our volunteers, our Social Worker, 1 Home Health Aide from the Visiting Nurses Dept., and 8 staff members from Our Island Home. In October, we will be sponsoring tuition and transportation costs for 4 professionals to attend the Annual New England Hospice and Palliative Care Conference, 1 of whom will be from the hospital's medical-surgical unit, 2 from Our Island Home, and 1 from our Palliative Care staff. We'll also be covering transportation expenses for 2 patient care assistants from ACDC (Adult Community Day Center) to attend a free, one day, off-island conference on Alzheimer's Disease. We've been able to offer such excellent opportunities this year thanks to a very generous grant from the Dorothy Egan Foundation designated for continuing education of direct care staff.

As we look to the coming year, we'll be continuing to develop our new services, providing more informational outreach, and converting our website to reflect our program changes. As always, we acknowledge and appreciate our colleagues in other departments and agencies with whom we work so that patients in our community receive the best care possible by their health care team, and, of course, we continue to deeply appreciate the work of Hospice Care of Nantucket Foundation, without whom none of this would be possible.

Heartfelt Thanks to the Dorothy Egan Foundation

We express our sincere gratitude to the Dorothy Egan Foundation for the generous gift given to us to be used to continue the education of staff who provide direct patient care. Particularly in the present economic environment, most of the continuing education we've been sponsoring both for our own department's staff and that of our colleagues in other departments and agencies would not have been possible. This has afforded the opportunity for many staff from agencies without money in their budgets for professional development to continue to enhance their skills in caring for persons nearing the end of life.

As always we sincerely thank those families who have directed that memorial contributions be made to Hospice Care of Nantucket Foundation. Because of these donations we are able to continue to provide services free of charge.

Patient Care Statistics - 9/1/08-9/1/09

Comprehensive care patients: 25 patients - this includes physical, psychosocial, spiritual care to patients in any setting - home, hospital, or nursing home - and support for their families both during the illness and for approximately 1 year after the death of a patient. The total number of patient care days was 1828 for this group of patients. The average length of time on our services was 75 days, with a median of 28 days. Total number of days spent in the hospital was 227, while total number of days spent at home or nursing home was 1601 days. (Note: there were 59 deaths from any cause in Nantucket during this period.) (25 patients were served in the prior year also.)

Palliative & supportive consultations:

(These are consultation sessions for person in earlier stages of illness.)

Total number of individuals for private sessions
37 (11 in prior year)

Total number of private sessions
150 (63 in prior year)

(84 of which included relaxation/massage) (63 in prior year)

Total number of individuals for Cancer Support Group sessions
23 (12 in prior year)

Total number of Cancer Support Group visits
131 (75 in prior year)

Community grief consults

(These are grief support sessions for community members who experienced the death of a relative who was not a "comprehensive care" patient.)

Total number of individuals
15 (12 in prior year)

Total number of private sessions
86 (87 in prior year)

(57 of which included relaxation/massage) (61 in prior year)

Caregiver support services: (These figures reflect services for mostly "non-comprehensive care" family members.)

Total number of individuals
23 (17 in prior year)

Total number of private sessions
46 (71 in prior year)

(8 of which included relaxation/massage) (49 in prior year)

Total number of individuals for "Time Out" group sessions
7 (5 in prior year)

Total number of "Time Out" group visits
53 (50 in prior year)

TOTALS:

Total number of clients served:
130 ("comprehensive care patients & families are counted as 1 client) 82 prior yr.

Total number of "comprehensive care" patients/families
25 (25 in prior year)

Total number of non-comprehensive care clients
105 (57 in prior year)

Total number of non-comprehensive care client visits
466 (346 in prior year) (149 of which included relaxation/massage/yoga) (209 in prior year)