## Palliative & Supportive Care of Nantucket

For Patients, Families, and Caregivers Touched by Life-Threatening Illness and Grief

## Currents

Vol. 27, No. 2

## The Importance of Planning Ahead

#### *By Dianne Bein, MSN, FNP-BC, ACHPN Program Director/Clinical Manager*

Upon reflection of my first year with PASCON, I am reminded of the many changes we have experienced and the opportunities that have emerged from those changes. We are thriving, but also experiencing some mild growing pains as a result. We have added a staff member, and the PASCON Board is developing a new 5 year plan. We are looking at the direction of healthcare in general, and we are examining how PASCON can develop programs to increasingly meet the needs of our island community.

We will soon move into our new home on the hospital campus - not inside the beautiful new facility, but nearby in our own thoughtfully designed space in the Anderson Building, where renovations are currently underway. We are creating, in partnership with the hospital, an environment that is homelike and comforting, so we can carry on our work of serving the Whole Person - mind, body, and spirit. There we will be able to serve our patients, train our many volunteers, and develop new programs that many of you have requested.

One of the highlights of my first year here has been bringing the Rev. Dr. Gloria White-Hammond to the Island. I would like to share a little bit about the purpose of her visit and why the type of change she specializes in is so important for all of us.

Dr. White-Hammond is both a Medical Doctor from Tufts and a Doctor of Ministry from Harvard, with her own 500-member congregation in Jamaica Plain. Because of her unique background, she can speak to palliative and EOL (end-of-life) care as both a physician and a minister, and she does just that with palliative departments across the country. She also teaches at Harvard Divinity School.

The initial purpose of our invitation was to train the Nantucket clergy and their active lay members on the Nantucket Interfaith Council to help individuals in their own congregations in planning ahead for their EOL care. The two-hour meeting eventually morphed

### **Tree of Remembrance** *Healing Through the Holidays*

While this season of reflection is a favorite for many, it can also be a difficult time for any of us who have experienced loss. The holidays will soon be upon us, and PASCON's Annual Tree of Remembrance Ceremony has just recently been held, a wonderful tradition that evokes gratitude for all those we've lost over the past year or perhaps years.

into two meetings over three days that included medical and nursing staff at NCH and an interview on the Frank and Mary on Nantucket cable TV show. Our guest talked about the "Conversation Project," a national public engagement initiative with a goal to have every person's wishes for EOL care expressed and respected.

We knew that the need for better

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Healing is a slow process, and some of us need more time to work through the pain and "move on." There's no right amount of time, and it takes as long as it takes. Thankfully, time eventually becomes the healer, and this ceremony has served for many years as an important moment in that healing process.

This Tree of Remembrance that grows in the park across from the Jared Coffin House is now covered in lovingly inscribed scallop shells that will eventually be returned to the sea. This community gathering has helped many of us come just a step closer to healing and finding some closure in loss.

Through this holiday season, as we pass by and glimpse that lighted tree, I hope it will remind us that we are all on this journey together and that none of us who have ever loved are spared the pain of loss (this includes the loss of a family pet companion, where the pain can be equally devastating). That tree serves to remind us to reach out to members of our community as they relive lifelong holiday traditions in the absence of those who have been an integral part of their lives.

Thank you to Rev. Linda Simmons and to Jenny Paradis and her friends from St. Paul's choir for such a special service. Thank you to Jason Curtis and NIR and to Michael Misurelli and his crew at J&M Landscape Services for getting the garden ready. Thank you to Michael Getter of Dune for hosting a lovely reception.

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#### PALLIATIVE & SUPPORTIVE CARE OF NANTUCKET FOUNDATION

## Our Services at a Glance

#### Individualized Comprehensive Care

Through consultations and follow-up care, we offer a broad range of physical, psychological, social, and spiritual care for persons with life-threatening illness and their families. Services are provided by our interdisciplinary team of professionals and volunteers and are aimed at providing education, support, and symptom control from the time of diagnosis through cure or, if cure is not possible, through advancing illness and end-of-life. All of our services are provided in the most appropriate setting for our patients' needs – in our office, at home, in the hospital, or in the nursing home.

#### Caregiver Support\*

- Coaching for Caregivers one-on-one consultations with our Nurse Practitioner and Palliative Care Counselor on any aspect of care; individualized assessment of needs and individualized plans for support;
- Time Out a professionally led group providing education, support, and socialization with other caregivers – held on the 2nd and 4th Wed. of each month from 1-2:30 pm in our office;
- De-Stressing to Cope a group or private educational session focusing on caregiver issues and stresses, positive self-care, and techniques for coping;
- Lending Library of caregiver-related topics.

#### Grief and Bereavement

Education, basic counseling, and referral for persons coping with the death of a loved one.

- Private individual sessions
- Grief Support Group led by Palliative Care Counselor Bonnie Fitz-Gibbon, Ph.D. - held on the 1st and 3rd Wed. of each month from 1-2:30 pm in our office. Call for details.
- Focus is on:
  - Understanding the grief process
  - Actively doing one's grief work
  - Optimizing wellness through diet, exercise, stress reduction, mind/body modalities, coping strategies;
  - Coping healthily and effectively.

#### Cancer Survivorship Program

Working collaboratively with a person's physician(s) and other health care practitioners, we provide an extra layer of support to help deal with the cancer and its impact on body, mind, and spirit through:

- Education, counseling, and support
- Patient navigator services
- Pain and symptom control
- Stress/distress management
- Mind/Body education and care
- Advance care planning
- Comprehensive care as needed
- Coping with Cancer Support Group held every other Mon. from 1-2:30 pm in our office
- Marla Ceely Lamb Cancer Fund
- Survivorship Services
- Referrals as needed
- End-of-life care as needed

#### Children's Services

- Direct care to children with lifethreatening illness and family support;
- Guidance for parents of children coping with the illness of a loved one;
- Education and support for families of children grieving the death of someone close;
- An extensive library of resource materials available for loan.

#### Volunteer Aid/Companionship

Trained volunteers are available to help patients and families and can:

- Provide respite breaks to caregivers
- Drive to doctor's appointments
- Assist with household chores
- Do errands
- Take patients on outings
- Help record personal history
- Play music
- Listen to their story
- Provide companionship
- And more

\*The Caregivers' Connections Program of PASCON is funded in part by the MA Executive Office of Elder Affairs and the Federal Administration for Community Living by a contract from Elder Services of Cape Cod and the Islands.



Foundation Mike Misurelli President Sharon Woods Hussey Vice President Nancy Moylan Treasurer Emily Molden Secretary/Clerk Laura Belair Marianne Felch Lou Gennaro Andrea Giletti Kimberly Higgins Cathy Lennon

Duncan Macallister

James F. Meehan

Nancy Newhouse

Sherry Rowsey

Carrie M. Riden Executive Director

#### Program

Dianne Bein, MSN, FNP-BC, ACHPN Program Director/Clinical Manager Charlene Thurston, RN, ANP Director Emeritus Timothy Lepore, MD Medical Director Sarah Munsen, LICSW Social Worker Rev. Linda Simmons, MDiv Chaplain

Libby Tracey, RN, MSN, AOCN Palliative Staff Nurse

Bonnie Fitz-Gibbon, Ph.D., LMHC Palliative Care Counselor Ginnie Faria Volunteer Coordinator

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The Hospital Thrift Shop presented PASCON with \$10,000 to help facilitate its move from Sherburne Commons to the Anderson Building on the NCH campus.

## PASCON Adds to Board

PASCON Foundation is pleased to announce the election of Andrea Giletti to its Board of Directors. Andrea is a retired Oncology Nurse, BSN, MSN and has been a full-time Nantucket resident since 2014. She brings professional palliative care and hospice experience as well as personal experience accompanying both parents through end of life at Connecticut Hospice. Recently Andrea was inspired by the vital support PASCON provided to a close friend throughout her cancer journey and end of life. She hopes to support PASCON's unique mission of continued service to patients in all community settings. She would like to focus on increased community awareness of palliative care and the message that palliative care is not a binary choice and that curative and palliative care can be offered simultaneously. She would also like to focus on the problem of late uptake of hospice care which she sees as a local and a national problem. She's hopeful that the new location of PASCON's office will become an exceptional facility with a beautiful environment in which to provide supportive services for patients and their families and education for caregivers.



Our Annual Daffodil Planting took place November 12th at the New Street triangle in Sconset. 5,000 bulbs were planted by **J&M Landscape Services** and **Champoux Landscape** who donate the bulbs, materials, and labor every year to keep this fabulous tradition alive.

## Thank You, Ginnie!

Ginnie Faria has been the first voice you hear and the first face you see at PASCON for the past 17 years. Her warm smile and her calm, caring way have helped ease countless patients into our programs and services. The people calling or walking through our doors are often reeling from a frightening diagnosis or a devastating loss. We can't imagine a better person to guide them on their way.

Ginnie has also run our amazing patient care volunteer program and managed the Marla Ceely Lamb Fund for many years. She led



Bonnie Fitz-Gibbon and Ginnie Faria

PASCON's Swim Across America team as Captain and has given her free time and energy to every fundraiser we've had.

Former Program Director Charlene Thurston had this to say. "Ginnie has been the best program assistant we could hope for in all of her years working for our palliative care program. In everything she does, she is careful, competent, respectful, compassionate, and always goes above and beyond the call of duty to help others. She's been loved and trusted by all our patients as well as our staff and has been such a wonderful colleague. She will be truly missed!"

Patient care volunteer and Board member Nancy Newhouse occasionally fills in for Ginnie at the PASCON program office and said that she can immediately hear the disappointment in a patient's voice when they learn Ginnie is away. "The comfort she conveys is all encompassing," according to Nancy. "Her help is without end."

Program Director Dianne Bein echoes these sentiments, describing Ginnie as "compassionate, patient, ever positive, sensitive, caring, generous, and a gift". Though here just one year, Dianne has quickly come to rely on Ginnie as her "right arm, sounding board, confidante, cheerleader, editor, wise counsel, and good friend". Dianne says that she "will miss her dearly, as will so many others she has helped along the way as the face of our program."

As she hangs up her many hats at PASCON this month, we thank her for her dedication to this community. Retirement (and her husband Howie) beckons. Well deserved, but we will all miss her presence.



Visit www.pascon.org today.

### 26th Annual Dreamcatcher Dinner and Auction - June 9, 2019



### Swim Across America's Nantucket Island Swim - August 24, 2019



## **10 Years of Support** Many to Thank for Art Show

This is the 10th year that Quidley & Company has hosted an art auction benefiting PASCON and the Marla Ceely Lamb Fund. It began quite simply with a desire to give back to the community and has resulted in \$150,000 for the two charities.

Owner Chris Quidley and former business partner Rob Giacchetti had both lost a parent to cancer. One of their em-



Quidley & Company owner Chris Quidley and Gallery Director Adam Sodofsky

ployees had been diagnosed with cancer and was facing the burden of traveling on and off for treatment. Inspired by an art show they'd seen in their travels, the idea for the first Stroll art show was born.

The format has changed significantly over the years, but the goal has always remained the same: raise as much money as possible for these two vital organizations. The current show relies on a secret bidding process to encourage shoppers to bid high for the works they want most. And it offers artists a modest recompense on some works to encourage participation.

Don Van Dyke, a past president of the Artists Association of Nantucket, worked with Chris to develop the new format which benefits both the artists and the charities. Don also had firsthand experience with loved ones battling cancer, and as a passionate island artist, he knew there was a whole legion of artists eager to help.

This show is collaboration and generosity in action. Chris and his staff put a great deal into it in the months preceding, soliciting and then storing works, and then they turn over half of the gallery to the show on one of the busiest retail weekends of the year. Cape Cod Five Cents Savings Bank has sponsored the event most years since 2011, and Stop and Shop, Stacey Perry, and Cumberland Farms have helped with the reception at different times. Wayne Petty and Laura Anderson of Nantucket Frame Center were tremendous supporters in the early years, on hand to frame purchased works right on the spot. Chris' children have handed out candy canes and hot chocolate and Town Crier Eric Goddard adds to the festive feel ringing his bell to welcome buyers and announce winning bids. Over 200 artists have participated since it began, some contributing all 10 years.

Thank you to everyone involved in this terrific event! Special thanks to former Board member Gussie Beaugrand and current Board member Sharon Woods Hussey.

### Contributing Artists Have Included

Cary Akins Joan Albaugh Jeffrey Allen Ginger Andrews Kate Pelletier Andrews Valeri Arnold-Osley Sean Beavers Rob Benchley Edward Benedict Bruce J. Beni Colin Berry India Blake Nikoline Bohr Chris Bourbeau Susan Briskman Angie Brooksby Dan Brown Judy Brust Maud Bryt Kwan Buadam Philip Buller David Burgess Tim Campbell Rosemary Campobasso Marilyn Chamberlain Wayne Chinnock Eva Cincotta Barbara Clarke Nathan Coe Frederick Collord Matthew Cornell Stephen Coyle Susan Covne William R. Davis Tricia Deck John Devaney MJ Levy Dickson Linda Dolphin Claudia Kronenberg Marshall Dubock William Duffy Yvonne Duval Tara Young Early Maryalice Eizenberg John Evans Howard Faria Julija Mostykanova Feeney Sandra Flavin Elle Foley Marcus Foley Flick Ford Margaret Fox Robert Frazier Trey Fuccello Paul Galschneider Robert Gambee Jennifer Geller Dorothy Gennaro Julie Gifford Marcus Goulding Tine Kirkland Graham Joan Griswold Louis Guarnaccia Hilario Gutierrez Sonia Hale Beverly Hall Kerry Hallam David Hallidav Alesia Hamideh Duncan Hannah

Meredith Hanson T. S. Harris Tracey Harris Madeleine Hay Greg Haynes Gay Held Mary Heller Katie Hemingway Dani Henke G. S. Hill Megan Hinton Eric Holch Jim Holland David Huberman Randy Hudson Sharon Woods Hussey Oriana Ingber Julia Jensen K. Tyler Johnston Maryann Jones Patricia Jones Donald Jurney Joanna Kane Michael Keane Suzanne Keating Carol Keefe Kathleen Kelliher Darius Kersulis Cynthia Kirkwood Kathleen Knight June Koch David Kooharian Garv Korlin Whitney Kreb David Kuhn Paul La Paglia Mary Emery Lacoursiere Ben Larrabee Kenneth Layman Susan Lazarus Barbara Leger Katie Trinkle Legge Donna Levinstone Sherre Wilson Liljegren Sue Lingeman Leslie Linsley Miki Lovett Michael Lynch Jon Marshall Bay McClure Jan Purdy Metcalf Paul Michetti Thomas Mielko Jane Mihalik Bob Miklos Javier Mixco Susan Moss George Murphy D. Clyde Myers John Neville TM Nicholas Elizabeth Nicholson Kit Noble Diana Dunbar Northrop Matthew Oates Tom Olcott Ellen Metzger O'Shea Doug Owen Anne Packard

Gary Paller Anthony Panzera Teal Parker Stephen Pitliuk Betsy Podlach Helen Sharp Potter Scott Prior Chris Quidley Peter Taylor Quidley Deborah Quinn-Munson Romana Rainey Cate Raphael Mindy Reasonover Lauri Robertson Sharon Farrell Robinson Forrest Rodts Sergio Roffo Phyliss Rosser Edwin Rudd Donn Russell Margaret Saliske Valerie Sampier Christine Sanford Penny Scheerer Jess Hurley Scott Michael Shemchuk Peter Sheppard Dave Shevlino Peggy Silverstein Nancy Simonds Josh Simpson Hunt Slonem Jessica Sosebee Kevin Stanton Robert Stark III Audrey Sterk David Stern Aleta Steward Anne Sutherland Joseph Swain Elizabeth Lockhart Taft Valerie Thomas Tony Thompson Luke Thornewill Sage Goldsmith Tremaine Anne Troutman Lynn Tucker Jocelyn Sandor Urban Susan Van Campen Deborah Van der Wolk Donald Van Dyke Kathleen Kasmar Van Lieu Sharon Van Lieu Marilyn Vaughn Meghan C. Weeks Jo Ann Welch William Welch Caroline Weld Neeltje Westerlund Buzz Williams Barbara Willis Sid Willis Marilyn Wills Evan Wilson Michael Wodynski Karen Woods Loretta Yoder Lucinda Young Linda Zola Lori Zummo

# Marla Ceely Lamb Fund

Thank you to all the donors and volunteers who have sustained the fund since the list we published in our spring newsletter:

- Meredith Lamb and her friends and family of volunteers, Faregrounds, and everyone who made donations and purchases at the Annual Dinner and Auction last month
- Nantucket Police for their No Shave November campaign
- ShepleyWood Products for their 24th Annual Wide Open Charity Golf Tournament in September
- the Dorothy Harrison Egan Foundation
- the estate of Patricia Griffin
- Yale Whiffenpoof Alumni for their Charity Concert this summer
- Brian Glowacki for his Night of Comedy in April
- Poets Corner Press
- Hyline Cruises
- families who named the fund as a beneficiary
- generous unsolicited individual community gifts
- Chris Quidley and Adam Sodofsky of Quidley & Company and all the artists contributing to the Stroll Art Show

The Marla Ceely Lamb Fund is managed and administered by PASCON so that every dollar raised and donated can go directly to patient travel expenses. We urge anyone who is a cancer patient or who knows a cancer patient to call 508-825-8325 and arrange to take advantage of this fund.





(508) 825-8325 for cancer patients to access the Fund

## A few words from Ginnie Faria upon her retirement

I became the administrator of the Marla Ceely Lamb Cancer Transportation Fund 9 years ago. At the time, I wasn't sure how I was going to manage it within my part-time work here at PASCON. But it has become a role very close to my heart, and my favorite part of the job. I will be sad to leave the patients and families that I have grown to love when I retire this month.

We want to assure the community that my replacement will be here to serve those who need to travel offisland for treatment...that the fund is here for them. We also want to remind people that the fund is not an insurance reimbursement, nor is it a state or federal grant. It is totally supported by the generous and hard-working members of the community of Nantucket.

Since the fund began 27 years ago, over 500 patients have been served. And over the past ten years, over \$600,000 has been dispersed!



Members of the Nantucket Police Department showing off unshaven faces as part of No Shave November.

#### Planning Ahead (cont. from p. 1)

EOL planning here on Nantucket, as elsewhere, is great, but her focus underscored my struggles as both a nurse practitioner with my patients and as a daughter with aging parents. I believe that I, along with my colleagues, have a responsibility to discuss what is happening as we watch our patients, parents, spouses, and our own bodies inevitably age. Yet, few of us ever ask the necessary questions related to aging, illness, and mortality.

I have been unsuccessful in my own attempts to speak to my 90-year-old parents over the last few years about their wishes and desires for EOL care. Several years back I had carefully selected a stack of prepared papers and timidly sat down with them to inquire about their wishes - presenting materials like Five Wishes, MOLST forms, Advance Directives, and everything else my social worker colleague could put together for me to help them plan for EOL care. But my parents were not ready to talk about a time when they would no longer be able to care for themselves. It seemed to them that this time would never come.

Why didn't I insist, push a little harder, empathize with them about loss and hard decisions, and then persist? Now I find myself making decisions for those who have historically made decisions for me! And I am sad for them. Why hadn't they told us what they wanted for these final years? Or better yet, why hadn't we insisted they prepare us? Why did none of us ask these difficult questions years ago when our parents were clearheaded and empowered, rather than frail, unstable on walkers, and often forgetful or confused?

What's worse is that I find myself struggling to put my own EOL choices on paper through an Advance Directive. I'm not sure exactly why, since I don't like uncertainty, and I'm typically all about being in control. I've never been comfortable when others speak for me, yet why would I hand off these consequential decisions to others?

It seems I'm not alone. According to recent data, more than 90% of us say talking with loved ones about EOL care

is important, but only one quarter of us have done anything about it. Although 7% of us have had an EOL conversation with our physician, NP, or PA, fewer than 25% have put our wishes in writing, even though 82% of us say it's important. Where is the disconnect?

As each of us grows older, most of us say we want to retain control over our lives. When we let fear or anxiety stop us, we're shifting the responsibility to others we love. We are actually making a decision by default, that these are the ones who will one day make those tough decisions for us. Experts say we are delaying the inevitable because Advance Directives are difficult, and it hasn't been part of our culture. Yet, as one *Forbes* article points out, we plan for everything else: marriage, kids, vacations, travel, major purchases, and retirement.

None of us want to face the end of our lives. The Dad I love has difficulty accepting that he may not live another 10 years to 100, as his grandfather did, despite failing kidneys, difficulty walking, and frequent trips to the ER where staff know him by name. I never want to take away hope from my patients or from my dad. Being human has a 100% mortality rate, yet we as humans are not great at accepting that mortality.

For many of us, death is frightening and final. For others with religious or spiritual beliefs, hope lies in something more to come. But none of us can know. What we do know is that whatever comes next is different than the present and we are most fearful of the unknown. Most of us are also good excuse makers and procrastinators. It's much easier to take the Scarlett O'Hara (*Gone with the Wind*) approach and "think about it tomorrow."

We may put this matter off because we think we're too young, too busy, or will always have tomorrow. Perhaps we don't want to "tempt fate". Or we wait for our trusted physicians to bring up the subject, while they're waiting for us to do the same. What that leaves behind is a legacy that makes the lives of our loved ones so much more difficult and often traumatized.

In cases where no Advance Directive existed, several survivors have told me

that they continue to feel great anxiety, many years after the death of their loved one - not because they believed they had done something wrong, but because they didn't know if they had done something right.

No one forces us to face these EOL issues. While questions about EOL are becoming more commonplace in hospitals and medical offices across the country, we have a long way to go. Many practitioners don't want to have that tough conversation, and patients are happy to avoid it as well. It takes time and schedules are full. It's also uncomfortable and can be awkward. It puts our mortality at center stage and we are forced to look it squarely in the eye. As humans we avoid psychological pain at every turn. Many providers fear that EOL discussions will cause their patients distress. If we are asked often, maybe we will eventually get the message that this really is important, and especially so in a culture that's not comfortable with death as a part of life.

Regardless of why we put these decisions off, it's important to begin the process. It can be done in stages and we can remind ourselves that this is not really "all about me." By facing our fears, we are making our own decisions and taking this burden off our families. It is never easy, regardless of our age, but it's our right and responsibility to do so.

As my adult children see me struggle with the care of their grandparents, I reassure them that this will not happen to them. I will tell them exactly what I do and don't want at the end of my life, while I can still make clear decisions. There will be no divisiveness or animosity where my children disagree about what they think I want. I owe them that.

As we remember those who are no longer with us during the holidays and enjoy the company of those who are, my hope is that those of us in that 75% will begin the process of planning ahead. EOL planning relieves the burden we might otherwise put on loved ones, while also giving us the dignity and peace we all deserve at the end of our lives.

I look forward to the reflection and celebration that this season brings, and to the promises, opportunities, and changes we will welcome in 2020!

## Thursday • Friday • Saturday

Final Bids 3 pm Saturday • Quidley & Company • 26 Main Street

# Annual Art Auction

## Benefits PASCON & Marla Ceely Lamb Fund

**Robert Frazier** 

Cary Akins Joan Albaugh Ginger Andrews Kate Pelletier Andrews Valeri Arnold-Osley Susan Briskman Kwan Buadam Barbara Clarke Susan Coyne Tricia Deck MJ Levy Dickson Julija Mostykanova Feeney Sandra Flavin Elle Foley Marcus Foley

Tracey Harris T.S. Harris Greg Haynes G.S. Hill Sharon Woods Hussey Julia Jensen Maryann Jones Suzanne Keating Carol Keefe Nancy McGivney Jan Purdy Metcalf Robert Miklos Susan H. Moss Teal Parker Scott Prior Cate Raphael Sharon Farrell Robinson Forrest Rodts Sergio Roffo Penny Scheerer Aleta Steward Don Van Dyke Meghan Weeks Caroline Weld Michael Wodynski Karen Woods Lucinda Young

\*list as of printing - please check www.pascon.org for complete list



PALLIATIVE & SUPPORTIVE CARE OF NANTUCKET FOUNDATION

<u>A Partnership in Caring</u>



Funded by the Palliative & Supportive 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 and Supportive Care 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.