Maine Hospice Council, Inc.

Promoting Excellence in End-of-Life Care

February 22, 2007

Good morning Senator Rotundo, Representative Fischer, Senator Brannigan and Representative Perry. My name is Kandyce Powell, Executive Director of the Maine Hospice Council and Center for End-of-Life Care (Council). It is my pleasure to update you on the Council's activities and how we maximize our limited resources.

As many of you know, the Council is a 501c3 membership organization with a multidisciplinary board, four full-time staff and a budget of $400,000. Since 1984 the vision of the Council has been to create a more socially responsive environment for end-of-life care. This has been accomplished by collaborating with interested parties and developing more formal partnerships in order to address the many difficult issues facing our friends, neighbors, and family members.

Since 1989, the Council has been grateful for an annual general fund appropriation that has not only provided important revenue, but also underscored the importance of the public/private approach necessary to sustain progress in end-of-life care. Even though our budget has increased significantly since 1989 our funding request from the general fund has not. Over the years we have tried to maximize our resources and diversify our revenue. The Council has been very successful because of the creativity of its board and staff. It has diversified its' funding sources, leveraged grant monies and built on data from previous projects to develop new projects and programs. The Council also remains prudent with its resources. For example, as a result of a grant in 2005, the Council was able to hire a development director; however, after evaluating the position at the end of the grant funding, it was determined that sustaining a development position was not fiscally prudent. This was a difficult decision, but one that had to be made.

This past year has been one of tremendous activity, highlighted in June by the publication of "Pain Management at the End-of-life: A Physician Self Study Packet" (PSSP), made possible with a grant from the American Alliance of Cancer Pain Initiatives (now known as the Alliance of State Pain Initiatives) at the University of Wisconsin. Additional funding for this document has come from American Cancer Society, Maine Health Access Foundation and the Office of Substance Abuse. Not only has this publication been successful with physicians and other prescribers both in Maine and out-of-state, it addressed a request from the Judiciary Committee to address issues of continuing education for physicians (LD 1842).

Over the past year the Council has:

- Worked with Dr. Kaowale Bankole Medical Director of the Minority Health Division of the Portland Public Health Department, because end-of-life needs of many individuals and families from ethnic communities are poorly understood and often not adequately addressed.
- Begun to address end-of-life care as a potential public health issue in light of the projected change in age demographics over the next ten to fifteen years and the unacceptably low utilization of hospice services.
- Continued to work with Maine's Office of the Attorney General to address Consumer issues around en-of-life care. In the summer the Council will be hosting six Town Hall meetings, moderated by the Attorney General, to hear what is working well and what aspects of end-of-life care need to be changed.

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- Worked with hospice programs on access, utilization and quality issues because there are many individuals and families in our communities who are unable to access hospice services even though they may qualify.

- Continued developing our partnership with Togus VA Medical Center and the Maine Veteran's Homes because the needs of veterans are overwhelming. Approximately 1,800 veterans die each day in the United States and a great many more will require services for on-going mental health issues, chronic illness and disability. The majority are not enrolled in the VA, but will receive services from community based organizations and agencies. This year, approximately 25% of those who receive hospice care will be veterans. In 2006, the Council, in cooperation with Togus and Maine Veterans Homes published a brochure for veterans and their families. We continue to hold community educational opportunities for veterans and their families to talk about issues such as advance directives, pain management, and hospice resources. *(Please refer to Hospice/Veterans Brochure)*

- Continued working with the Department of Corrections and Maine State Prison (MSP) system to address policies and provide training for staff. The prison population is growing, aging and dying in place. There has been an ongoing interest at the MSP to develop a hospice program. Maine has been selected for a site visit by the National Corrections Association because of our collaborative work over the past five years.

- Received a grant from Channel 6 for three months of free television spots. This opportunity will raise awareness of hospice services in Maine and offer more people the resource information they need to make informed decisions about their care.

- Continued to develop a marketing and distribution plan for the PSSP, with the additional funding from our partners.
- Continued to provide a placement site for graduate and undergraduate students.

Because of our successful programs and initiatives, our work has earned a national reputation. We conduct market research every five years; hold Town Hall meetings and focus groups in order to develop a work plan that is demand driven. As one respondent on our survey said, "I support the work of the Council because it addresses the needs of the people and does what it says it will do."

The Council receives no funds from Medicare, MaineCare or other 3rd party payers. We try not to overlap with the development efforts of direct service hospice programs; however, in order not to do this we have to be very creative in our fundraising and development efforts. This often creates a huge challenge and places a heavy emphasis on grant writing.

To sustain and grow our work for the future, we need your continued support. None of us are creative enough, or intelligent enough to change end-of-life care by ourselves. We must work together to create the kind of system that will provide accessible, high quality care for our friends and neighbors.

With gratitude,

Kandyce Powell
Executive Director

MaineLink

Newsletter of the Maine Hospice Council and Center for End-of-Life Care

Volume 7 Number 1, Winter 2007

Maine Pain Initiative Announces New Educational Opportunity for Maine Physicians

Pain Management at the End of Life: A Physician's Self-Study Packet (PSSP) was published by the Maine Hospice Council and released in June of 2006. Since publication, this important resource has also been cited as a Best Practice by the *National Hospice and Palliative Care Organization* and the *Alliance of State Pain Initiatives.*

Developed by the Maine Pain Initiative (MPI), a multi-disciplinary committee of the Maine Hospice Council, the packet covers the clinical issues, ethical considerations and common myths of pain management. The packet is accredited for continuing medical education credits and includes tools for clinicians, such as pain scales, pain assessment guides, equianalgesic charts, "Pain Pearls," web resources, and a pocket guide.

"A comprehensive, straight forward, best practice for managing pain at the end of life. An exceptional reference," says Diana Rae, RN, C, MSN, co-chair of the MPI.

"Many physicians have told me they would prefer self-directed education," says Kandyce Powell, Executive Director of the Maine Hospice Council. "We are pleased to offer this opportunity to Maine physicians and other prescribers."

"Making the right thing easy is what this is all about," says Peter Goth, MD, Maine Hospice Council board member and Co-chair of the Maine Pain Initiative. "This packet addresses the issues of greatest importance to physicians when making decisions about appropriate pain management."

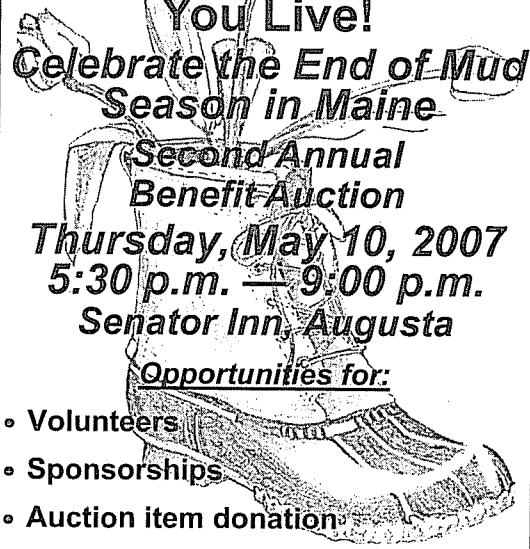
Project Director Judith Tupper from the Muskie School of Public Service comments, "The finished product represents a commitment to patient centered care for Maine families and a tremendous collaborative effort." Other participating organizations include the American Cancer Society, Maine Board of Licensure in Medicine; Maine Board of Osteopathic Licensure; Maine Medical Association; Maine Office of the Attorney General; Maine Osteopathic Association; Massachusetts Pain Initiative; as well as the grantee, the Maine Hospice Council.

This project was supported with a grant from the American Alliance of Cancer Pain Initiatives, as well as additional funding through the American Cancer Society, Administration on Aging, and the Maine Office of Substance Abuse.

Copies of the packet may be obtained by completing the request form on the Maine Hospice Council website www.mainehospicecouncil.org, or by calling MHC at 800-438-5963. A non-credit version of the packet is available for download on the Maine Hospice Council web site.

FDA Cites Maine Hospice Council Resource

The U.S. Food and Drug Administration's *Center for Drug Evaluation and Research* has cited the Pain Management at the End of Life: A Physician's Self-Study Packet (see story in left column) in a recent alert to healthcare professionals. This guide is one of two physician education training tools reference by the FDA in a recent alert.



Inside this issue:

Letter from Kandyce Powell

On Christmas Eve I received a phone call from a friend I had not seen, nor heard from, in years. Nothing too unusual about that you might say, which on the surface is absolutely true; however, the reason for the call was profound.

Tom (not his real name), began by apologizing for the untimely nature of the call but he figured the chances of catching me at home would probably be good. It was apparent that this was not just a friendly call to wish me a Merry Christmas and catch up. The breathless nature of his speech and tone of voice told me more than his words. I said, "Tom, what's wrong? Are you okay? You sound short of breath." The conversation that followed touched me deeply. He said he needed help, and needed to talk with someone he could trust. His story unfolded.

Tom was told he had lung cancer a few months prior; however, he was quick to tell me he wasn't calling to complain about the diagnosis, after all, he had enjoyed a wonderful life. I think it's important here to tell you a bit about Tom. He was intelligent, well informed about many things (including health care), and not a person who ever seemed to be afraid of advocating for himself or others.

What he was incredibly angry about was the amount of pain he was experiencing. Over the months he had seen no less than six specialists, all very competent in addressing his disease. I asked him which healthcare professional was coordinating his care and he said he didn't know. According to Tom, no one seemed to be too concerned about the quality of his day-to-day living, nor did they seem to consider his symptoms a priority. I told him that he had a right to be treated with dignity and respect; to have his report of pain taken seriously; to have it assessed regularly and to have his treatment adjusted if it was not easing his symptoms.

It was at this point in the conversation that Tom asked if he could put his significant other on the phone. An hour later, after discussing resources and a process for advocating for what Tom needed, we said our good-byes. Tom's story lingered with me over the holidays and in the weeks since. The power of his experience and thousands of compelling stories like it need to be heard in a way they have not been heard before.

Which brings me to the subject of engaging the community in end-of-life care. How important is it? It's HUGE, and yet, according to Robert Wood Johnson and others, community engagement remains the missing piece. Social movements like hospice require critical mass in order to force the kind of system change that we would like and need to see. Why has it been so long in coming?

According to Casarett, Karlawiish and Byock, in a recent article, "Advocacy and Activism: Missing Pieces in the Quest to Improve End-of-Life Care", "Patients and families face at least four obstacles in becoming effective activists for better end-of-life care."

1. Patients and families dealing with life-threatening illness are not part of a cohesive community accustomed to political action.

2. Patients and families are often too vulnerable to take vigorous action.

3. Voluntary health organizations... may be reluctant to promote end-of-life care, feeling that acknowledging death may be counterproductive to raising money for research into life-prolonging treatments.

4. Any efforts to generate activism will likely encounter cultural avoidance and denial of dying and death.

So what do we do? Well, we give our friends and neighbors opportunities to tell their stories; we give them information so they learn what they don't know; we reach out to the underserved; we engage the media and we convene town hall meetings to listen to what is working well and what needs to be fixed. We also need to collect data and do cost/benefit studies to produce the kind of evidence that convinces policymakers and insurers that there are underutilized cost effective programs that are known to produce high quality outcomes and save the health care system money.

Most importantly, we need to work together, for Tom and all the people in our communities who depend on us. Please join the Maine Hospice Council as we embark on a very ambitious work plan to address these important issues with the people of Maine. Your help and support is critical!

Kandyce

Maine Center for End-of-Life Care

Medicare Hospice Access and Utilization: A Conversation

The Maine Hospice Council and Center for End-of-Life Care is beginning an ambitious project to examine access to the Medicare Hospice Benefit. Maine currently ranks 48th among the 50 states in Medicare Hospice Benefit utilization. The need for hospice services will continue to grow given the projected demographic changes anticipated in both the over 65 and 85 age groups; therefore Maine can no longer continue on its current course. A comprehensive examination of the impediments to access is warranted.

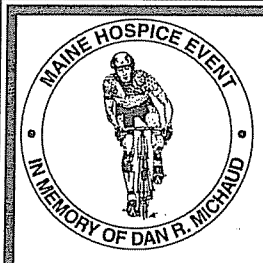
The Council has begun this process with a planning meeting, and will convene a Stakeholders Conference to be held in Portland on March 30. *"Medicare Hospice Access and Utilization: A Conversation"* will feature a panel of representatives from states with high Medicare Hospice utilization. The Conference will also offer opportunities to discuss challenges to increase utilization and suggestions for change. Facilitation by an independent party will provide objectivity.

The Muskie School of Public Service will be engaged to gather input at the Conference to design a survey tool for interviews. This tool will be critical in collecting data. Interviews will be conducted of hospice programs, associations and other referral sources. Recommendations will be made and a final report will be published. An implementation strategy will be developed.

This ambitious project will require a great deal of collaborative effort. Information from this project will be invaluable to policy makers as they continue to grapple with health care reform. It is well known that programs like the Medicare Hospice Benefit provide quality outcomes for consumers as well as a cost benefit to the health care system.

To date, support for this project has been received from the Carpenter Foundation, Davis Family Foundation, Maine Health Care Association, AARP, Lighthouse Hospice Foundation. and the Roman Catholic Dioceses.

More information on this Conference can be found on the website: *www.mainehospicecouncil.org*



Save the Date!
Saturday, August 25, 2007
Maine Hospice Event
In Memory of Dan R. Michaud
(formerly the Dan Michaud Memorial Ride)

Come Ride or Walk!
Downtown Brunswick

Across the Disciplines

Social Workers Focus Group

The Social Workers Focus Group on End-of-Life Care meets bi-monthly at the Maine Hospice Council office in Manchester. The focus group began meeting in 2005 after the Listening Conference was held.

In 2006, at the June meeting a presentation was given by Frank Magrogon of Kno-Wal-Lin. Frank had attended the April NHPCO Conference in California. He provided 3 pages of notes and handouts from the various social work secessions. Some of the areas addressed included; the expanded role of the social worker on the IDT, and up-to-date information related to management of bereavement and grief as well as other pearls of wisdom.

The next meeting is scheduled for March 8 from 3:00 to 5:00. All social workers are invited to attend.

Volunteer and Bereavement Coordinators

The newly formed Coordinator's network group met January 10, from 10:00 to 2:00 at the MHC Conference Room in Manchester. The meeting had been planned by Kathy Leavis, Volunteer Supervisor with HealthReach Hospice and Volunteers of Kennebec Valley and Donna Jacobs, MHC staff to build a good working relationship among the providers. We were pleased to welcome fifteen volunteer and bereavement coordinators from across the state. Kandyce Powell discussed "Trends in Hospice" that included the issues of access and utilization.

Over lunch everyone had time to network and trade business cards. After lunch we looked at future meeting dates and topic areas. Meetings will be scheduled quarterly.

The group chose "Vital Volunteerism," a look at volunteer management, to be the topic at the next meeting April 2, from 10:00-2:00. Lunch will be provided.

Please join us at the next meeting. If you would like more information please call the Council office at 626-0651.

Maine Hospice/Veterans Partnership

What is the Hospice/Veteran Partnership?

HVP is a coalition of people from the Department of Veterans Affairs (VA), veterans homes, and community organizations working together to ensure that excellent end-of-life care is available for our nation's veterans and their families. The HVP of Maine is part of a national network.

Why were we formed?

The mission of the HVP is to establish an enduring network of hospice and VA professionals, veterans, volunteers and other interested organizations working together to provide quality end-of-life services. The HVP was formed to provide leadership, technical assistance, and program development recommendations in the following areas:

Improving veterans' access to hospice and palliative care across practice settings, so they can receive care at the time and place of need.

Strengthening relationships between state hospice organizations, VSOs, VA organizations and veterans homes.

Creating a comprehensive community engagement plan designed to reach veterans.

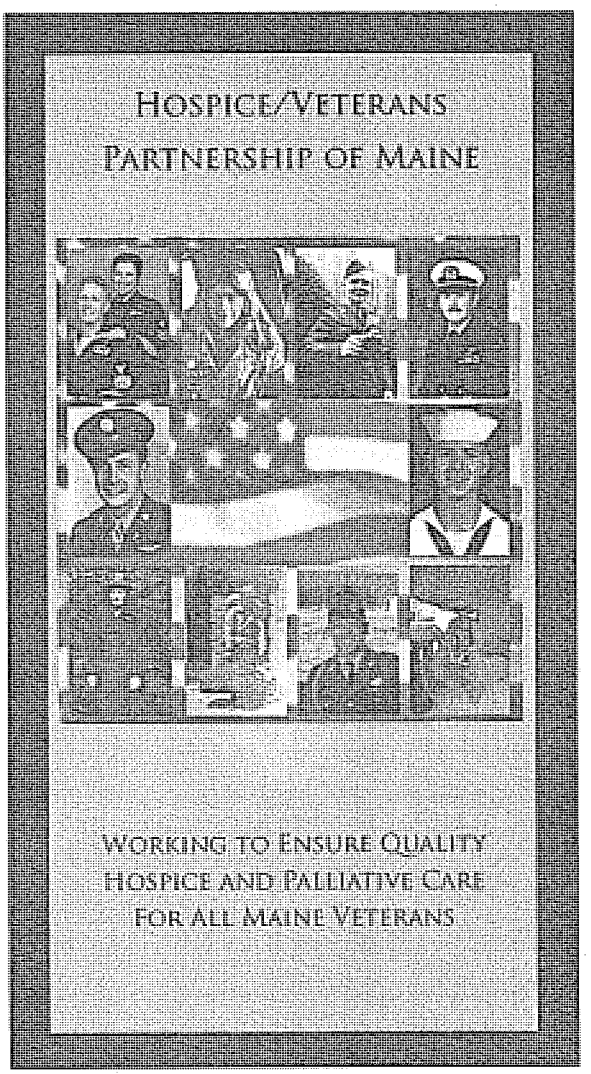
Who are our members?

Maine's HVP includes representatives from the Maine Hospice Council, the Maine Veterans' Homes, Togus VA Medical Center, Veterans Service Organizations, end-of-life coalitions, community hospice agencies, as well as other organizations and individuals interested in improving end-of-life care for veterans.

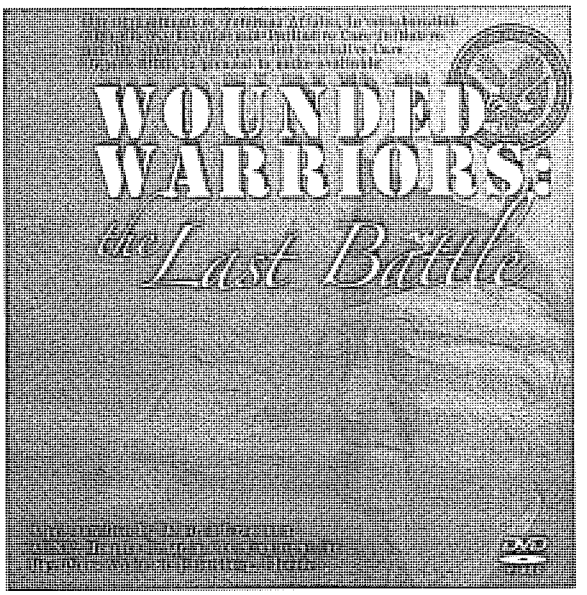
How can you get involved?

Contact the Maine Hospice Council at *(800) 438-5963.*

Getting the word out on 92 Moose — Dale Marie Clark (left), Hospice Volunteers of Waterville Valley, and Amy Line (right), MHC Board President, were recently interviewed by Renee Nelson (center) of Citadel Broadcasting. Amy discussed the Council's work with the Hospice/Veterans Partnership as well as sharing that hospice services are available statewide to veterans and their families. Dale Marie talked about the direct services her volunteers provide veterans.



The new HVP Brochure and copies of the *Wounded Warriors* DVD are available from the Maine Hospice Council office.



Come Celebrate With Us
23 Years of Progress!

Maine Hospice Council Annual Meeting

Thursday, June 21, 2007
Sebasco Harbor Resort

Golf Scramble Fund Raiser
8:00 to 3:00
18 hole tournament
Prizes for:
- Low team score
- Longest drive
- Closest to pin
- And more!

Elegant Evening
5:00 to 9:30
A special evening for our members and friends.

5:00 Happy hour
6:30 Fine Dining
8:00 Entertainment

Get your team ready now!

For more information, visit our website
www.MaineHospiceCouncil.org
Or call
(800) 438-5963

Around the State

Androscoggin Home Care and Hospice

In January 2006, Karen Flynn, RN, BSN, CHPN was appointed Hospice House Manager. Karen brings over 20 years of nursing and management experience to this position and has been with AHCH since 1989. Most recently, Karen was the Hospice Program Educator for the agency.

I am also pleased to share that Dr. Roger Austin Hospice House Medical Director is now at the facility full-time. He is a wonderful asset to our team.

The second 7-patient suite wing was opened March 1, a full month ahead of schedule to better meet patient demand. In the first 6 months of operation, 121 patients have been cared for at the Hospice House. The average stay for patients is 8 days.

On a very rainy Saturday in early May more than 40 boy scouts, their leaders and family members worked for 7 hours cutting trees and preparing the hard packed path. Materials and use of construction equipment to build the path were donated by local businesses.

The path measures over 300 yards and ends at a small circular perennial garden. The scouts have included three stone benches for sitting at points through out the path. The final steps, landscaping and planting were completed June 10th.

Maine Art Glass Studio in Lisbon Falls is creating a custom-made stained glass window for the door and accompanying side panels leading into the sanctuary. The 5' window incorporates a tree of life in the fore ground with mountains and a river behind. The design flows into 10 side panels surrounding the main door. A special feature of the piece is the native Maine stones and gems being incorporated into the design along the riverbed.

Artisans worked on the piece and volunteered their time and talents. Maine Art Glass Studio donated the materials. The window was installed just in time for our first anniversary.

Hospice House cared for 261 patients in our first year of operation. While we are

(Continued on page 7)

Maine Hospice /Corrections Partnership

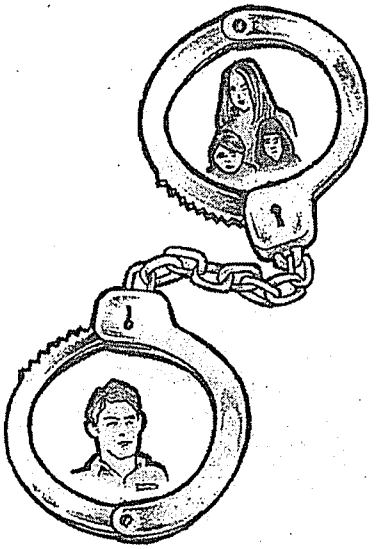
Submitted by Leida Dardis

In 1999, the Executive Director of the Maine Hospice Council, Kandyce Powell, met with Maine State Prison staff to provide information about hospice services. Interest in developing a hospice prison program was supported by Warden Merrill who appointed a committee to develop a program. The composition of the Committee was a varied blend of staff and community volunteers from different disciplines who were committed to the goal of offering a range of services to the prison population. Committee members have included the Executive Director of the Maine Hospice Council, a community psychiatrist, Department of Corrections' Central Office staff, Volunteers of America, facility medical and program staff.

Since then, the Committee has instituted a variety of hospice program components. These include staff training on issues of dying and death, training for medical staff on pain management, a biennial memorial service for prisoners, and an expansion of the bereavement support group for prisoners (now known as Healing After Loss Group(which had been started in 1998 by the facility psychiatrist, Dr. Diane Schetky, who is a Committee member. Recently, Dr. Schetky offered to develop and teach a curriculum to new staff on issues of personal loss. Her class raises the awareness of the range of losses an incarcerated offender may experience from the loss of his freedom and family connections to the death of a loved one.

With the Department's male infirmary housed at the prison, the Hospice Committee is committed to developing another important hospice program component that would allow selected and trained prisoners to participate in the support care of terminally ill prisoners. Over the next six months, the Committee will be working on a proposal for an end of life program component that meets DOC policy and procedures and American Correctional Association standards.

GRIEF AND LOSS WHILE DOING TIME



LOSS IS PART OF LIFE

Grief and loss are common in prison, but rarely discussed. There are as many types of losses and reasons to grieve as there are different people in prison.

A brochure created by inmates is available from the Council.

As part of the effort to promote hospice services in correction, the Maine Hospice Council organized a Hospice and End of Life Care conference held in June, 2001. It was a collaborative effort between the Maine Hospice Council and the Department of Corrections that was sponsored by the Maine Criminal Justice Commission, Volunteers of America, the National Institute of Corrections, and pharmaceutical manufacturer Purdue Pharma. The impetus for this conference evolved from the realization and recognition that little attention has been paid to people dying in our prisons and county jails. The conference drew a wide audience with noted speakers from multi disciplines. The Maine State Prison Hospice Committee is also reviewing plans to host another conference in the future.

The partnership between the Maine State Prison and the Maine Hospice Council has brought elevated awareness of end of life issues to the prison. This partnership has enhanced services for prisoners and provided staff with greater knowledge and sensitivity.

Volunteer Opportunities

The Maine Hospice Council has many opportunities for volunteers. These include:

Office help

Mail production

Event support

Committee participation:

- Auction
- Development
- Maine Hospice Event (formerly the Dan Michaud Memorial Ride)
- Maine Pain Initiative

Please call the Maine Hospice Council toll-free at (800) 438-5963 to ask about these and other volunteer opportunities.

A Sincere thank you and farewell to Nancy Hayner and Jean Sequeira for all your work over the years to help the Annual Retreat to be the great success it has been.

We will truly miss the "raffle queens."

The Maine Hospice Council and Annual Retreat Team.

Maine Pain Initiative Symposium

Pain Management at the End of Life

Maine Pain Initiative

April 25, 2007
8:00 a.m. to 4:00 p.m.

University of Maine at Presque Isle

Featuring:

Diana Rae, RN, C, MSN - Pen Bay Medical Center

Greg Burns, RN, BSN - The Jason Program

Peter Goth, MD, FACEP - Emergency Physician

Elizabeth Hart, MD - Maine General Medical Center

Kandyce Powell, RN, MSN - Maine Hospice Council

Continuing Education

Application for continuing education credits have been submitted. For information about specific discipline credits, please call or visit the Council website.

www.mainehospicecouncil.org

(800) 438-5963

Around the State (Continued from page 5)

always mindful that we are caring for patients at the end of life and there are tears, the Hospice House is not a sad place. It is warm and welcoming, and it is not unusual to hear laughter.

Hospice of Hancock County

Several exciting transitions are underway at Hospice of Hancock County (HoHC) in Ellsworth. On June 30th, much beloved Barbara Clark retired from her post as Executive Director. Community members and hospice colleagues alike are grateful for Barbara's 12 years of outstanding service and leadership, and wish her well in this next leg of her journey.

In response to Barbara's retirement, the two newly defined staff positions of Executive Director and Program Director were created. Serving as the new Executive Director, Jody Wolford-Tucker, Ph.D., joined HoHC this spring and brings a diverse background of experience in community human service agencies and educational administration. Jody's leadership will focus in the areas of administration and development.

More recently in June, Sara Hayman, MSW, M.Div., joined HoHC as Program Director, a new position created to give added emphasis to the importance of volunteer services and patient care. In this new role, Sara is responsible for volunteer recruitment, training and support, as well as community-based educational programming regarding end-of-life care.

In this 25th year of service, Hospice of Hancock County is excited about with the future will hold.

Downeast Hospice

If you haven't visited us at our new office at the new Calais Regional Hospital, you are in for a treat. Ann Sullivan (office manager), June Archer-Gillespie (bereavement coordinator) and I are enjoying our new space made possible by a private donation. We are very happy and grateful to have such a nice location in the new hospital. We have a small lending library and many materials that can be requested for free. Our number is still 454-7521 ext. 126. We continue to use the space generously provided to us by Down East

(Continued on page 10)

Kno-Wal-Lin Homecare and Hospice Moves Forward With the a Freestanding Hospice House In Mid-Coast Maine

In a continuing effort to better serve our communities Kno-Wal-Lin is building a Hospice House proximate to the administrative offices on their Pleasant Street site in Rockland, Maine.

This will be the first Medicare-Certified, free standing Hospice House in mid-coast Maine. The expected date to start construction of the Kno –Wal Lin Hospice House is summer of 2007 with anticipated opening scheduled for summer of 2008.

According to Sarah Dwelley, Hospice Program Manager "Our Hospice House will care for patients at the latter stages of a terminal illness where the complexities of their care would necessitate an inpatient medical environment that has 24-hour nursing care. In addition to caring for terminally ill patients, the Hospice House staff will also provide support for the families. The Hospice House is actually a combination of care for the dying as well as a place of hospitality for the families who are grieving and want to be with their loved ones during their final days. This type of specialized care is best given in an environment that is away from the hustle and bustle of a hospital or rehabilitation facility."

Donna DeBlois, Executive Director adds "Our House will reflect a New England Farmstead with the "Big House, Little House, Back House, Barn" configuration. The "Houses" will be connected by enclosed passageways and surrounding courtyards with four-season gardens. The "Big House" is home to the community living room, dining area, kitchen, and pantry. The "Little House" consists of the administrative offices, conference room, and workspace for the staff. Our "Back Houses" are home to our seven patient suites, each with a private bath and an attached living room area to accommodate family. The library and sanctuary are also part of the "Back Houses". The Barn contains the garage, staff lounge, storage, and the electrical and mechanical rooms."

The atmosphere of the Hospice House will be one of peace and tranquility with plans to have a rotating art exhibit from local artists adorning the walls, an indoor garden with water fountain, and a baby grand piano. The interior design and furnishings will "look like, act like, and feel like home".

End of life is a time of bringing one's life to a close. It is our hope that our Hospice House will provide the atmosphere as well as caring and compassionate staff to help our patients and families achieve peace and comfort during this final journey.

Artist rendering of outside of house.

Maine Hospice Council, Inc.

The Maine Hospice Council exists to ensure the continued development of Hospice and Palliative Care in Maine. The Council provides education and technical assistance regarding end-of-life care, as well as advocacy for terminally ill and bereaved persons regarding quality-of-life issues throughout the state.

MaineLink is the official newsletter of the Maine Hospice Council, Inc., reflecting news, issues, and views of the Council and serving as a forum for the Hospice community throughout the State of Maine. Comments and questions should be addressed to: MaineLink Editor, PO Box 2239, Augusta, ME 04338. (800) 438-5963 (207) 626-0651 Fax: (207) 622-1274. *MaineLink* may be distributed and reproduced in whole or part, provided appropriate reference is given and materials are distributed without charge.

Hospice and Palliative Care Center in Fort Kent

In less than three months after applying to the IRS to establish non-profit status, the Board of Directors of *le Homestead* received that confirmation on May 1, 2006. At their first annual Board meeting, members were able to boast at being a registered 501-(c)(3) organization, thanks to the benevolence and diligence of the Genesis Community Loan Fund and the Maine Housing Technical Assistance Consortium. "We are ecstatic!" expressed Therese (Terry) Caron, President of the future hospice and palliative care center and native of Fort Kent. "Now we can roll up our sleeves and join the rest of the communities of the Greater St. John's Valley in an attempt to emulate the ingenuity of these people with their 'can-do-spirit'. This is the time when we begin to build collaborative relationships and partnerships to plan and implement the project.

"After much discernment, discussion and sound advice, I made the commitment to found *le Homestead* in Fort Kent, whose purpose is to create and maintain – with quality and compassion - an in-patient hospice and palliative care center for elders in the greater St. John Valley who are living with a life-limiting condition," says Terry. "The concept of 'hospice' in Maine has been experienced by families and loved ones who are dying, as a service rendered within the confines of home. However, there are times when caring for a gamily member simply is not feasible. When symptoms cannot be managed at home, when families are having difficulty coping with an imminent in-home death, when there is a waiting list at a skilled nursing facility, or an agency cannot offer 24-hour coverage, *le Homestead* commits to providing a warm, homelike setting in a beautiful and serene atmosphere while ensuring round-the-clock quality hospice and palliative care, a full range of services with Medical Director, Karen Hallee, MD, palliative care registered nurses, ancillary staff an dedicated volunteers." Terry assures respite care will be offered to adults of all ages provided there are open beds.

The six-resident in-patient hospice facility will be housed in a single-story building with generously-sized patient rooms to accommodate familial presence during a loved one's final stage of life. Each room will have actress to an interior garden, *(le Jardin d'Esperance)* and mediation room *(l'Hermitage)*. All patient rooms will also have access to a porch that wraps around the building. Basement space will be reserved for a center for grieving children and families to be known as *Memere's Chair*. The hospice facility has been designed to acknowledge and respect *la vallee's* Acadian and Franco-American traditions.

We invited Julie Shackley, Androscoggin Home Care and Hospice, to our November board meeting to give a presentation on their inpatient facility. The presentation will help us in our start-up efforts. A meeting is planned for the latter part of February. The focus will be on the proposed project feasibility study. To learn more about us, please visit lehomestead@yahoo.com.

The Gosnell Memorial Hospice House

In late September 2006, Hospice of Southern Maine (HSM) began construction of the *Gosnell Memorial Hospice House*, southern Maine's first freestanding end of life care facility! The 16,000 square foot, 18-bed residence will provide care for more than 700 patients and families each year. On land donated by Agnes DesFosses in Scarborough, construction is expected to be complete in summer 2007. With Maine ranking 48th in the country for its utilization of hospice services, our community understood the need for an inpatient facility and responded by pledging $5.5 million in capital campaign gifts in order to proceed with the construction phase.

The layout of the house emphasizes privacy, dignity, and inclusion of family members. The design includes a common living room, dining area, a kitchen (available to families as well as dietary staff), and a sanctuary for quiet contemplation or spiritual comfort. The rooms will be home-like with comfortable furnishings including a pullout sofa to enable family members to spend extended periods of time with their loved ones. The house will be fully equipped to provide sophisticated medical, nursing and other professional care. Its Scarborough location ensures easy access for families, professionals, and other caregivers from both counties.

Hospice of Southern Maine has seen a tremendous amount of growth since they began providing services only 2 years ago. In 2006, each month HSM provided services to approximately 50% more patients and families in York and Cumberland Counties than in 2005.

Annual Joe Mayo Award

"When you do the common things in an uncommon way, you will command the attention of the world."

George Washington Carver

The Maine Hospice Council created the Joe Mayo Award in 2001 to recognize the untiring efforts of The Honorable Joseph Mayo, Clerk Emeritus of the Maine Hospice of Representatives, to improve end-of-life care for all Maine citizens.

Joe's efforts were particularly remarkable, as he was diagnosed with ALS in the previous year. His commitment to work on this issue at a time of tremendous personal challenge was inspirational to all who worked with him. Because of Joe's efforts, end-of-life policy in Maine is a model for every state in the nation.

In all areas of end-of-life care – policy, direct care and administration – there are people who truly shine because of their creativity, determination, commitment, caring and extraordinary effort. These people do "common things in uncommon ways" and deserve our attention and acknowledgement.

For more information about the award, nomination process, or for nomination requirements and forms, please call the Council at (800) 438-5963 or visit our website.

Previous Award Recipients:

2001 The Honorable David Madore
2002 Dr. Larry Harcourt (awarded posthumously)
2003 Dr. Thomas J. Keating
2004 Steven Rowe, Attorney General of Maine
2005 Rita Melendy
2006 Androscoggin Home Health and Hospice

Nominations will be accepted through April 15.

The 21st Annual

Thomas Nevola MD Symposium on Spirituality and Health

Tuesday, June 5, 2007

to be held in the Augusta/Waterville area.

Christina Puchalski, MD.

Keynote presenter,

author of

A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying

Brochures will be available and distributed in late April.

Around the State *(Continued from page 7)*

Community Hospital in Machias when I am in that part of Washington County.

I am so moved by the work Down East Hospice volunteers do for families in need and how giving you all are.

Coming up: March 11 - Benefit Dinner at Bernardini's Italian Restaurant in Calais. March 22 - hosting the Hospice of America live Teleconference. For more information about us or any of the above events - 454-7521 ext. 126 or downeasthospice@yahoo.com

Hospice Volunteers in Mid Coast Maine

Starting on Thursday, March 8, 2007, Hospice Volunteers in Mid Coast Maine will begin its Spring session of *The Hospice Approach to Living with Dying* Community Education/Volunteer Training Program. This program will run from 4:00 to 7:00 p.m. for 10 consecutive weeks, ending on Thursday, May 10. Anyone from the Mid Coast area who is interested in the training, please call Kathy Goddu, Director of Volunteer Services at (207) 729-3602 for more information.

The Maine Hospice Council is a membership organization. Individual, program, and organization memberships are available. The Maine Hospice Council and Center for End-of-Life Care would like to thank our membership for their continued support.

For more information on membership, please contact the Council by phone (800) 438-5963.

Hospice Provider Members

Androscoggin Home Care & Hospice
Beacon Hospice, Inc.
CHANS Home Health & Hospice
Coastal Family Hospice Volunteers
Community Health & Counseling Services
Down East Hospice
Hancock County Homecare Hospice
HealthReach Hospice and Volunteers of Kennebec Valley
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Hospice of Southern Maine
Hospice of York
Hospice Volunteers: Center for Grief & Loss in Mid Coast Maine
Hospice Volunteers of Somerset County
Hospice Volunteers of Waldo County
Hospice Volunteers of Waterville Area
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EMMC Dialysis Unit
The Jason Program
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MaineGeneral Health Palliative Care Program
Maine Medical Center Palliative Care Program
St. Andrews Hospital and Palliative Care
Two Roads Maine

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Rev. Sudie Blanchard
Robert A. Fried, MD
Wendy Flaschner, LCPC

A Heartfelt Thank You to All Our Donors!

Your support of our work to bring quality end-of-life care to the people of Maine is very much appreciated. Please let us know if you'd like to become active in our many educational and community programs, advocacy, and research. Check our website for announcements about coming programs and many other resources.

(This list represents gifts received May 15 through December 31. Please accept our apologies if your name is missing below.)

Stewardship Circle

We are grateful for the leadership support provided by members of the *Stewardship Circle*. With gifts of $100 or more, these donors help establish a solid foundation for the Maine Center for End-of-Life Care. *To find out more about the Stewardship Circle, contact the Council office.*

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From our friends at *Two Roads Maine*

In past years we have gone to Big Wood Pond in January and skied across the pond to the cabin and yurts. I often wondered, even on the coldest days, when I looked back at my ski track and saw the water filling in your track, just how secure that ice really was. The locals drove their trucks on that same ice which gave me some measure of comfort.

In February we are heading to Canada and Lake Memphremagog. To avoid any chance of polar dips, we are driving into this beautiful house situated above the lake. It is a warm and very comfortable setting with beds and flush toilets — no cold outhouse seats on this trip! The dates are Feb. 15-18th.

Then in March, we are traveling Cumberland Island off the coast of Georgia. Cumberland Island is located about 40 minutes off of St. Mary's, GA by ferry. The island is a National Park site and we will camp at Sea Camp. This island has a rich history and many natural wonders to explore. The weather is usually warm (65-75 degrees) and the water is warmer than the warmest water on the hottest days in August in Maine. The dates are March 4-9.

If you have any interest in these events, please contact Two Roads Maine.

Two Roads Maine is a non-profit organization dedicated to supporting the health and well-being of individuals, families, and friends who have experienced a life-threatening illness, or who are at a major transition place in their lives, because of a life-altering change (perhaps due to an injury or the loss of an important relationship or job).

TWO ROADS MAINE
The nature of healing

PO Box 415, Freeport, Maine 04032
(207) 865-4517

We sincerely appreciate the contributions of all our donors. Your generous support will make an important difference to hundreds of families in Maine.

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Jeannie Scudder, Benjamin and Nina
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Pamela Shay
Romaine Turyn and Al Prysunka

We Only Must Believe

Blossoming, green, radiant before they fall
The leaves, like hair, do not fall in vain.
Chemotherapy renews our bodies
Like winter renews the trees.

Bare now, but soon the juices will warm and flow
Maple syrup, sweet, small green leaves, red flowers
Our blood grows strong. Cells renew themselves
Like leaves on now dormant trees.

We know these things. We only must believe.

Believe that leaves, and hair, and new blood
Are part of God's plan. Nothing is stagnant.
Life must move forward. Leaves fall. Cells die.
Hair falls, and grows back, like leaves
If we only believe.

After winter comes spring—
The full blossoming of things.
Then summer and fall—
We know all will soon sleep
But then awaken, if we only believe.

By Esther McCandless
January 2007

There Are Many Ways You Can Help!

Your gifts to the Council — today and in the future — will help to educate people in Maine about end-of-life care available in their communities. You will reach out to underserved populations, including veterans, people of diverse cultural communities, and those living with neuro-degenerative diseases like ALS, Alzheimers, and others. You can help to train hospice and other healthcare providers to better manage pain, to improve the quality of care, and to strengthen their organizations to effectively face the growing demand. And you will support research and advocacy around end-of-life issues that will enable more people to access the kind of high-quality care they desire.

Donate using the Form below.

Double your contribution with a Matching Gift from your company. Send us the required forms from your human resources representative along with your donation. We'll take it from there. It's easy.

Give Through Payroll Deduction. Designate the Maine Hospice Council with your payroll gifts through MaineShare, MSECCA, Community Health Charities of Maine, Combined Federal Campaign, or United Way.

Gifts of Appreciated Securities are welcomed and may result in capital gains tax savings, income tax deduction, and removing this asset from your estate for the estate tax purposes. Contact your broker or financial planner to designate Maine Hospice Council to receive your gifts.

With a Planned Gift you can help hospice while enjoying benefits through future estate tax savings, current income tax savings, creation of an income stream for life, and a reduction of capital gains taxes. You can make a financial commitment from your will, living trust, or other estate plan to support the continued work of the Council. Let your attorney or financial planner know you want the Maine Hospice Council to receive your planned gifts.

Our most important source of funding is gifts from people like you!

Your support of the Maine Hospice Council will make an important difference in the quality of life experienced by thousands of individuals and families needing end-of-life care in Maine each year.

The Council works with consumers to identify critical issues of concern around end-of-life care, and provides education, training, advocacy and research to assist hospice programs and other healthcare providers, as well as terminally ill and bereaved persons around the state.

Please help in this important work by donating today.

Thank you for your support!

Please accept my gift to the Maine Hospice Council:

☐ $30 ☐ $50 ☐ $75 ☐ $100 ☐ $250 ☐ $500 ☐ Other $_____

Name: _____

Address: _____

City: _____ State: _____ Zip: ____

Telephone: _____ Email: _____

Please make this donation a ☐ memorial ☐ tribute to: _____

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☐ Check made payable to Maine Hospice Council enclosed.

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☐ My employer will match my gift.

Employer name: _____

Thank You!

All gifts are tax-deductible.

Promoting Excellence in End-of-Life Care

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693 Western Avenue, Manchester
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What's Going On!

Mar 8	***Social Workers Focus Group on End-of-Life Care.*** Maine Hospice Council office. 3:00 to 5:00 p.m.
Mar 15	***Maine Hospice Council Provider Advisory Committee.*** Maine Hospice Council office. 12:30 to 2:15 p.m.
Mar 15	***Maine Hospice Council Board of Directors.*** Maine Hospice Council office. Board meetings are open to all interested parties. 2:30 to 4:30 p.m.
Mar 30	***Medicare Hospice Access and Utilization: A Conversation.*** (see story on page 3) Portland. 8:00 a.m. to 4:00 p.m.
Apr 2	***Volunteer and Bereavement Coordinators.*** Maine Hospice Council office. 10:00 a.m. to Noon. Lunch will follow the meeting.
Apr 25	***Maine Pain Initiative Symposium: Pain Management at the End of Life.*** University of Maine at Presque Isle. 8:00 a.m. to 4:00 p.m.
May 10	***It's About How You Live!*** Celebrate the End of Mud Season. Maine Hospice Council Annual Fund-Raising Auction. The Senator Inn, Augusta. 5:30 p.m. to 9:00 p.m.
Jun 21	***Maine Hospice Council Golf Scramble.*** Sebasco Harbor Estates. 8:00 a.m. to 3:30 p.m.
June 21	***Maine Hospice Council Annual Meeting: Celebrating 23 Years!*** Sebasco Harbor Estates. 5:00 p.m. to 9:30 p.m.
Aug 25	***Maine Hospice Event in Memory of Dan Michaud*** (formerly the Dan Michaud Memorial Ride). Brunswick. A fund raising event in partnership with Hospice Volunteers: Center for Grief and Loss in Mid Coast Maine- For more information, visit the Council website at www.mainehospicecouncil.org/dmmr/.

Please contact the Maine Hospice Council for more information on these or other Council events.
(800) 438-5963 or (207) 626-0651 www.MaineHospiceCouncil.org

Hospice

Market Research Survey

The Potholm Group

Executive Summary

May, 2005

Introduction

This May, 2005 survey consisted of 400 completed calls of Maine adults. The normal statistical margin of error for a study of this type is plus or minus .049 at the 95th level of confidence.

The Findings

Hospice

1. Maine Hospice has an extremely positive rating.
2. Of all respondents, 68.5% said they had a favorable rating of Hospice, only 3.5% had a negative while 18% were undecided.
   - This is an outstanding portrait and one of which the organization and its leadership should be very proud.
   - Those making over $46,000 were more likely to know about Hospice and give it high marks. One out of three people making less than $46,000 did not have an opinion about the organization.
   - All major ethnic groups gave Hospice nearly 70% approval.
   - While college graduates (82% positive) gave Hospice the highest grades, all other education groups came at or near 70% approval.
   - Age was the most important variable as one might expect. Those 18-25 had the highest undecided quotient (48%) while those over 60 had the lowest (11%). By a margin of 83% to 3%, those over 60 gave Hospice a favorable rating.
   - All religious affiliations gave the organization high marks, including 74% of Catholics and 73% of Protestants.
   - Men and women both give it over a 60% approval rating.
3. And of those who were very familiar with Hospice, the positives were 91% compared to only 4.5% who had negative opinions.
4. Of all respondents, 31% said they were familiar with the organization, 36% were not and 33% were unsure.
5. Of those who had used Hospice, less than 1% said they had not received services in a timely manner. 22% had received it within 24 hours, 34% received it within 72 hours and 64% couldn't remember.
6. Of those who had used Hospice, 84% found it to be a positive experience while only 4% found it to be a negative one.
7. Among all respondents, 50% said they would consider asking their family to seek hospice care if they were diagnosed with terminal or life ending illness. Only 5% said NO while 45% were undecided.
8. BUT only 42% said they would know whom to call. 43% said they didn't know and 14% weren't sure.
9. The term "palliative care" is not well known throughout the state. Only 18% said they knew what it meant. 82% either didn't know or were unsure.
10. This finding is something that the end of life care community must recognize and either embark on a huge educational effort or else find a new term. This one is not likely to penetrate the public consciousness on its own.

11. Respondents were also somewhat confused about the components of Hospice. 10% thought it was a volunteer program only, 16% thought it was a medical-nursing program only while 33% thought it was a combination of the two. But 42% did not know the nature of the program.

The Context

1. Respondents were equally divided on the question "I'm more afraid of dying than of death itself." 34% were, 42% weren't and 34% weren't sure.

2. But 97% agreed that: "People should have control over the end of their life."

3. Again, respondents were quite divided when it came to: "I wouldn't want to linger in pain but I wouldn't want to speed up the dying process. If I could have my pain managed, have adequate support and be assured that the costs would be covered, that would be good enough for me." 31% agree, 43% disagreed and 26% weren't sure.

4. There was, however, considerable agreement with the notion: "If a person has some control over it, there can be a value in the dying process, bringing closure to life and becoming closer to family and friends." 69% agreed, only 4% disagreed while 27% were undecided.

5. And most agreed that: "I don't actually believe I would have much control over the end of my life if I were to die hitched up to machines or on life support." 80% agreed, 8% disagreed and 12% weren't sure.

Choice and Dying

1. In terms of the place of dying, 29% would choose their home, 26% would choose in a hospital and 32% weren't sure.
2. Surprisingly, almost 70% did not believe that end of life care raised financial hardships or did not know. Even allowing for age differences, this is a very high figure.
3. 70% had never cared for someone who was dying.
4. 82% did not expect to be caring for someone who would die in the near future.
5. Only 35% were fearful of dying in pain, 41% were not and 24% weren't sure.
6. 26% were fearful about dying alone, while 46% were not and 28% weren't sure.
7. 28% were fearful about dying with unnecessary tubes to keep them living longer, 28% weren't and 41% weren't sure.
8. 40% did NOT believe that using a feeding tube was "a heroic measure." 19% believed and 41% weren't sure.
9. Only 17% said that Medicare, Medicaid and/or other private health insurance would pay for hospice and end of life care in the home while 12% thought Medicaid would but not Medicare. The rest were confused or didn't think that it did.
10. This is probably one of the most important finding in the whole study because it indicates that upwards of 70% of the population doesn't know that they are covered for end of life care!

That finding is particularly important because fully 65% of those surveyed said they would be more likely to use the hospice programs if they knew the costs were covered.

11. 56% of those surveyed said they did not support physician-assisted suicide, 20% did and 23% were undecided.
    - All major ethnic groups in Maine currently oppose physician-assisted suicide, including 60% of Francos, 70% of Irish and 60% of English.
    - Most educational levels also oppose it by margins of 2-1.
    - All income groups oppose assisted suicide.
    - All religious groups except "Other" Protestants oppose it by large margins.
    - Congregationalists, Unitarians, Methodists etc oppose it but by a margin of 43% to 30% with 27% undecided.
    - Those over 60 (81%) were most opposed to assisted suicide, while those under 45 were the least (29%) likely to oppose.
    - Assisted suicide is most strongly opposed (77% to 18%) by those who know about Hospice.
    - Republicans and Democrats both oppose assisted suicide while Independents are divided.
    - Women are much more likely to oppose assisted suicide (67%) then men (44% with 25% saying they are now undecided).
12. 45% said they could name an organization which assisted in matters of death and dying (see soft data Q#35 for specifics), while 55% could not or were undecided. Most put "hospice" somewhere in that name.
13. 55% said they had had a conversation with someone about how they want to die but 45% had not.
14. Only 50% of those surveyed said they had a living will, 50% did not.
15. Only 36% said they had a durable power of attorney for health care. 64% did not.

Authority Figures

1. Doctors remain powerful authority figures when it comes to these issues (100%).
2. Nurses also score well (90%).
3. Religious authority figures do have power for those who believe in their faith (70%).
4. In terms of a hierarchy, 98% would look to the doctor, 41% to the nurse, 35% to a family member, 24% to a social worker, 20% to a hospice volunteer, and10% to a chaplain, priest or minister.

The Costs of Caring: *Who Pays? Who Profits? Who Panders?*

BY LEONARD M. FLECK

Avastin, a widely used colon cancer drug manufactured by San Francisco-based biotech company Genentech, has proven a somewhat effective treatment for lung and breast cancer when administered at twice the normal dose. In February, the *New York Times* carried a story about Avastin's extraordinarily high price when used in this alternative way: $100,000 for one year's treatment—a figure fully twice the price of the normal dose, even though producing the higher dose costs the company little additional money. And the treatment yields only an average gain in life expectancy of five months—very modest relative to the cost.

What garnered media attention, however, was Genentech's novel justification for the price: "the inherent value of these life-sustaining technologies."[1] Rather than making the usual appeal to high research costs, the company cited the pricelessness of human life, implying a moral reason for the pricing decision. I will pass in silence over the obviously self-serving disingenuousness of this appeal. The fact is that many in our society—and perhaps a substantial majority—think human life *should* be thought of as priceless. That assertion can be taken in three very different ways.

We can take the pricelessness of human life to mean that the social worth of an individual (their social status or contribution to the national economy) should be completely irrelevant when it comes to determining how much society should spend to save or prolong that individual's life in the face of a life-threatening illness or accident—a worthy moral principle. Likewise, we should affirm the nonutilitarian view that the cost of saving either a life or a life-year should not determine by itself what will count as a just allocation of limited health resources when we cannot afford to save all the life-years medical technology may salvage. But we need to reject the view that we have a moral obligation to spend any amount of money to save all lives and life-years that medical technology permits. The result of adopting this view would be a gross distortion in our society's health care priorities that would not be just, compassionate, or prudent.

To see why this is true, let us look at some facts and reasonable projections. Health spending in the United States topped $1.8 trillion in 2004, roughly 16.3 percent of our gross domestic product (GDP), compared to 5.2 percent in 1960. Projections to 2015 show us spending more than $4 trillion on health care then—almost 20 percent of expected GDP.[2] Medicare spending in 2005 was about $330 billion. With deployment of the prescription drug benefit in 2006, spending will be about $424 billion—a price tag expected to rise by 2014 to $747 billion. Over the ten-year period ending in 2015, Medicare spending will exceed $4 trillion.[3] These figures are socially and politically problematic, especially in light of growing federal deficits.

Health policy analysts generally agree that emerging medical technologies drive escalating health costs.[4] Yet they and the public feel medical innovation should not be slowed or stopped—a conclusion I endorse as well. However, if we couple this belief with that third sense of the pricelessness of human life, the results are morally and economically disastrous.

♦ ♦ ♦

The problems posed by pricey medical innovation combined with a belief in the pricelessness of human life began with the passage of the 1972 End Stage Renal Disease (ESRD) amendments to the

Leonard M. Fleck, "The Costs of Caring: Who Pays? Who Profits? Who Panders?" *Hastings Center Report* 36, no. 3 (2006): 13-17.

Medicare program. Those amendments created a program that would pay for renal dialysis or transplant for virtually any U.S. citizen in kidney failure. The program was motivated by the fact that thousands of patients died every year in the late 1960s because they could not afford the cost of dialysis (roughly $90,000 a year per patient in 2005 dollars). The rhetoric at the time was that no one should be denied access to effective, life-sustaining medical technology simply because they could not afford it, and society pressured Congress to pass the program quickly.[5] Further, Congress believed that this was a unique medical technology, rather than the headwaters of a torrent, and it expected the program to top out in twenty years at a half billion dollars per year, meaning future costs would be reasonable. Unfortunately, Congress was wrong on all these points.

The dialysis program in 2005 cost about $20.5 billion and sustained the lives of 390,000 patients. Current projections show the program costing about $28.3 billion for 520,000 patients by 2010. Another 180,000 former dialysis patients will be kept alive with even more expensive transplants.[6] That Congress got the numbers wrong is excusable; that it endorsed the rhetoric of the pricelessness of human life is intolerable. The moral framework that should have guided these early decisions was that of health care justice.

Where was the moral mistake? The ESRD program paid for kidney transplants as well as dialysis. These were the early years of transplants; organ rejection problems meant success was spotty. By the late 1970s cyclosporin resolved that problem but created the question of whether to use public funds for other costly organ transplants. Why should renal patients benefit from public largesse, but not patients needing a heart or a liver? Aren't their lives just as priceless?[7]

Hemophiliacs have essentially the same predicament as renal patients: they need Factor VIII—a drug with annual costs in excess of $100,000—to halt bleeding episodes. But the government did not create any special program to save their lives. We can imagine the rationale constructed to defend this lack of response: the needs of hemophiliacs are too heterogeneous; not every bleeding episode is life-threatening; too many complex choices would have to be made among "deserving" and "nondeserving" episodes of bleeding. Government programs need bright lines. This, however, represents a second moral mistake.

Kidney failure draws the bright line that government seeks: dialysis works, sustaining lives otherwise doomed. However, that bright line obscures the morally problematic "ragged edge."[8] The fastest growing segment of the dialysis population are those over age seventy-five.[9] This is not to suggest that age by itself should disqualify anyone from dialysis. The real problem is that dialysis is being used more often to sustain very marginal prolongations of life at very great cost. Behind this is a subtle version of the pricelessness of human life claim.

Dialysis is a paradigm case of "rescue" medicine. Individuals faced with imminent death are given back the rest of their lives—for some, another fifteen to twenty years. But if human life is really priceless, then *all* prolonging of life through medicine is equally worthy of being supported, whether the gain is ten years or ten days. Likewise, if human life is priceless, then the quality of sustained life is irrelevant. Patients in the end stages of dementia or in a persistent vegetative state would have as much moral claim on prolonging their lives by dialysis as anyone else.[10] In short, the morally problematic syllogism is this: If dialysis is effective in saving life and we have chosen to fund it, then *every* instance must be covered—no rationing decisions can be made.

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The broader consequences of this thinking require our attention. Literally dozens of extraordinarily expensive cancer drugs and medical devices are now entering the market. All of them are "effective"—they prolong life. But the added time is often measurable in weeks and months, not years, which yields very high cost-effectiveness ratios—literally hundreds of thousands of dollars per quality-adjusted life year (QALY). Aggregate costs for all these treatments can quickly mount into the tens of billions of dollars. This has two morally problematic systemic consequences: employers drop or drastically restrict health insurance,[11] and health priorities get skewed in ways that are both unjust and uncaring.

As the cost of health insurance to employers mounts by double digits, more drop coverage as an employment benefit or increase copay requirements substantially. In either case, the economically disadvantaged have less access to needed health care than those who remain well insured and well paid.[12] More problematic still is the social hypocrisy fostered under these circumstances: Medicare or private health insurance plans that pay for $100,000 anticancer drugs like Avastin can affirm their endorsement of the pricelessness of human life (for those with the relevant insurance coverage) while drawing our gaze away from the uninsured or underinsured, as well as those who cannot afford the 20 percent copay their plan demands.

The other systemic consequence associated with these costly and marginally beneficial life-prolonging medical interventions—the distortion of health care priorities—is illustrated by a timely example from the United Kingdom. A major "grass roots" effort is underway there to compel the National Health Service (NHS) to fund access to the drug Herceptin as a first-line treatment for HER-2 positive women with breast cancer.[13] This drug costs about seventy thousand dollars for a full course of treatment. Approximately 25 percent of women with breast cancer are HER-2 positive, which means they are more vulnerable to a rapid and fatal metastatic process if the cancer is not defeated on initial diagnosis. Herceptin has been used as a second-line treatment for several years now, yielding only an average of five extra months of survival; but in late 2005, dramatic reports asserted that Herceptin increased survival by almost 50 percent when used as a first-line therapy.[14]

This way of reporting results certainly implies that Herceptin must be morally analogous to dialysis in its capacity to

save and sustain lives. However, a relative risk ratio is being reported, rather than an absolute risk ratio. Women not treated with Herceptin had a 17 percent chance of a recurrence of the cancer within one year. Herceptin reduced that figure by slightly less than 50 percent. That means that seventeen women would need to be treated to achieve that outcome at a total cost of about a million dollars to prevent a recurrence of breast cancer in that population within one year.[15] The inference we should not draw at this point (because there is no scientific evidence to support it) is that we have "saved their lives"—i.e., completely cured them of their cancer—yet this is exactly the impression most laypersons will have.

In the United Kingdom there are about sixty thousand people with ankylosing spondylitis (AS), a very painful and debilitating form of inflammatory arthritis largely striking young men. A relatively new therapy called anti-TNF can dramatically improve their overall functioning, but at a yearly cost of about twenty thousand dollars per patient. Most trusts in the NHS will not pay for the drug because it costs too much,[16] yet it costs far less than Herceptin. Why favor Herceptin? Herceptin "saves lives."

Dozens of expensive cancer drugs and medical devices are entering the market. All of them are "effective"—they prolong life. But the added time is often measurable in weeks and months.

Here we have an example of the moral insidiousness of a background belief in the pricelessness of human life. We can readily tolerate relievable human suffering in order to save very marginal portions of lives afflicted with a near-certain terminal condition. And as the number of these extraordinarily expensive, marginally beneficial interventions proliferate under the crusading banner of the pricelessness of human life, our health care priorities will likely become even more ethically askew.

In one recent news story, Dr. Leonard Saltz of Memorial Sloan-Kettering is reported as saying that drugs to treat colon cancer cost five hundred dollars ten years ago, while today's cost per case is about $250,000 for a thirteen-month gain in life expectancy.[17] The aggregate yearly expense of fifty thousand colon cancer cases treated this way would be $12.5 billion. Similarly, if each of the 155,000 individuals who die of lung cancer in the United States each year were given the drug Avastin at $100,000 each in order to achieve an average life gain of two months, $15.5 billion would be added to the cost of U.S. health care.[18] This represents a cost per life-year saved of $600,000. We surely ought to wonder whether we could save lives and misery among the uninsured and underinsured for a small fraction of that.

There are about 450,000 individuals in the United States who fall victim each year to sudden cardiac death. In theory most of those deaths could be prevented if each had an implantable cardiac defibrillator (ICD) at a cost of about $40,000 per device. We implanted 162,000 ICDs in 2005 in the United States.[19] Projections to the year 2010 suggest we might be implanting as many as 600,000 per year at a cost of $24 billion per year.[20] But criteria for the appropriate use of these devices are very crude, and consequently, they never fire for 81 percent of people who have had them for five years.[21] This looks like a major misallocation of health care resources, unless our starting premise is the pricelessness of human life.

One recent cost-effectiveness analysis suggests we should be implanting no more than fifty thousand ICDs per year, which will yield a cost per QALY of about $37,000.[22] As things are now, we purchase many of these QALYs at about $367,000 each.[23] Again, my point is not that cost-effectiveness analysis should be the foundation of moral judgments, but that it is a relevant consideration needed to counter the morally distorting influence of the pricelessness of human life.[24]

Consider the FDA's recent approval of a T-wave alternans test.[25] This test can identify a substantial portion of individuals who should *not* be candidates for an ICD, though they meet current criteria. It should reduce the candidate pool by about 33 percent—fifty-five thousand individuals per year at current implantation rates. However, the test is wrong in 1.2 percent of cases, which means five to six hundred will die suddenly from fatal arrhythmia preventable with an ICD implant. The cost of saving their lives would be about $3 billion. If we have a moral obligation not to put a price on human life, then we have to spend this money. This is a badly distorted moral judgment.

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In a recent survey of oncologists, 80 percent of them endorsed the idea of spending seventy thousand dollars on very expensive cancer drugs to give a patient two months more life.[26] I cannot imagine the moral argument to justify such a proposal. It would certainly not be rooted in any conception of either justice or social beneficence. If the appeal is to the pricelessness of life, then we ought to be honest in admitting that only very well-insured lives are priceless. The rest seem to be deeply discounted.

I have argued elsewhere that the need for health care rationing is inescapable, and that rationing decisions are more

likely to be just and caring if they are self-imposed through a process of rational democratic deliberation.[27] This is not a Rawlsian thought experiment; it is quite achievable (though not easily) in the real world. But a sustained and comprehensive deliberative process is necessary—one two-hour town hall meeting will not do. The public must receive a fair representation of the problem of health care cost escalation, the role of advancing medical technology in driving those costs higher, and the often very marginal benefits we collectively purchase with our health care dollars, as well as the opportunity to think through trade-offs and priority setting for a very large range of health care needs in the framework of a set budget. I believe the public is capable of this sort of thinking.

Oncologists can endorse expensive cancer drugs because they think only about cancer. They can ignore (though they should not) the question of what it means to be a just and caring society when we have only limited resources to meet virtually unlimited health needs. But the broader healthy public does have to struggle with the question of whether they can in good conscience deny an expensive arthritis intervention to afflicted individuals and impose five very painful and dysfunctional years on them in order to fund Avastin and provide two more months of life to someone with lung cancer. In such public conversations, properly managed, we develop our capacities for public reason and shared moral understandings, which we need now more than ever before.[28]

Oncologists can endorse expensive cancer drugs because they think only about cancer. The broader healthy public has to struggle with whether to impose five dysfunctional years on arthritis sufferers in order to provide two more months of life to someone with lung cancer.

1. A. Berenson, "A Cancer Drug Shows Promise, at a Price That Many Can't Pay," *New York Times*, Feb. 15, 2006.

2. S. Heffler et al., "U.S. Health Spending Projections for 2004-2014," *Health Affairs* 24, Supplement 1 (2005): W5-74-85.

3. Ibid., at W5-78.

4. D. Goldman et al., "Consequences of Health Trends and Medical Innovation for the Future Elderly," *Health Affairs* 24, Supplement 2 (2005): W5-R5-17.

5. R. Rettig, "Historical Perspective," in *Ethics and the Kidney*, ed. N. Levinsky (New York: Oxford University Press, 2002), 3-24.

6. J. Xue et al., "Forecast of the Number of Patients with End-Stage Renal Disease in the United States to the Year 2010," *Journal of the American Society of Nephrology* 12 (2001): 2753-58.

7. Actually, "political" considerations likely prevented a quick answer to this question. With kidney disease, everyone would be saved either by renal dialysis or transplant. But with other major organ transplants involving absolute shortages, the government would in effect be choosing which lives to save, then paying to save them—a visible and painful sort of rationing to which virtually no politician wanted to be linked.

8. D. Callahan, *What Kind of Life? The Limits of Medical Progress* (New York: Simon and Schuster, 1990), especially chapter two, "On the Ragged Edge, Needs, Endless Needs," 31-68.

9. L.A. Szczech and I. Lazar, "Projecting the United States ESRD Population: Issues Regarding Treatment of Patients with ESRD," *Kidney International* 66, Supplement 90 (2004): S3-S7. Figure 2 shows a growth in the dialysis population over age 75 from three hundred per million in 1981 to fifteen hundred per million in 2001.

10. There is something of an egalitarian thrust to this moral judgment, but I think this is as much an irrational egalitarianism as the pricelessness assertion is an irrational form of respect for human life. Both result in injustices that should not be tolerated.

11. T. Gilmer and R. Kronick, "It's the Premiums, Stupid: Projections of the Uninsured Through 2013," *Health Affairs* 24, Supplement 1 (2005): W5-143-51. They project an uninsured population of fifty-six million by 2013.

12. See E.L. Book, "Health Insurance Trends Are Contributing to Growing Health Care Inequality," *Health Affairs* 24, Supplement 3 (2005): W5-R5-77-79.

13. S. Boseley, "The Selling of a Wonder Drug," *The Guardian*, March 29, 2006. "Grass roots" is in scare quotes because drug advertising to consumers is not permitted in the United Kingdom. Companies such as Roche (maker of Herceptin) recruit patients as "activists" for their cause to pressure the NHS to fund these drugs. This article reports the story of Lisa Jardine, who was annoyed by Roche's persistent efforts to recruit her for what were really their marketing operations.

14. E.H. Romond et al., "Trastuzumab Plus Adjuvant Chemotherapy for Operable HER2-Positive Breast Cancer," *New England Journal of Medicine* 353 (2005): 1673-84; M.J. Piccart-Gebhart et al., "Trastuzumab after Adjuvant Chemotherapy in HER2-Positive Breast Cancer," *New England Journal of Medicine* 353 (2005): 1659-72.

15. A. Elliott, "Pros and Cons of Herceptin," *The Guardian*, April 3, 2006.

16. L. Moss, "Arthritis Patients Being Denied High-Cost Treatment," Press Association Newsfile, January 3, 2006, accessed through Lexis-Nexis.

17. C. Arnst, "Going Broke to Stay Alive: Rising Prices for Cancer Treatments Are Making Patients—and Doctors—Balk," *Business Week*, January 30, 2006: 36.

18. "Cancer Drugs of the Not-Too-Distant Future," May 6, 2002, accessed at http://www.cnn.com.

19. A. Agnvall, "Learning Fractions: Experts Debate Wider Testing of Heart Risk Factor," *Washington Post*, March 7, 2006.

20. S. Pauker, N. Ester, and D. Salem, "Preventing Sudden Cardiac Death: Can We Afford the Benefit?" *Annals of Internal Medicine* 142 (2005): 664-66. See also Z. Goldberger and R. Lampert, "Implantable Cardioverter-Defibrillators: Expanding Indications and Technologies," *Journal of the American Medical Association* 295 (2006): 809-18.

21. A. Gehi, D. Haas, and V. Fuster, "Primary Prophylaxis with the Implantable Cardioverter-Defibrillator: The Need for Improved Risk Stratification," *Journal of the American Medical Association* 294 (2005): 958-60. They conclude, "There is clearly much room for improvement in patient selection and thus more cost-effective management." See also G.H. Bardy et al., "Amiadarone or an Implantable Cardioverter-Defibrillator for Congestive Heart Failure," *New England Journal of Medicine* 352 (2005): 225-37.

22. S. Pauker et al., "Preventing Sudden Cardiac Death."

23. S. Al-Khatib et al., "Clinical and Economic Implications of the Multicenter Automatic Defibrillator Implantation Trial-II," *Annals of Internal Medicine* 142 (2005): 593-600. The reader is reminded that there is no cost-effectiveness for "the device itself." Cost-effectiveness depends entirely upon how the device is used with various patient populations. Most candidates for the device have serious heart disease that puts them at greatly elevated risk of death from associated complications. If patients have an ICD implanted and die from their heart disease within three years of implantation (the device never having fired), then the cost-effectiveness for that cohort will be $367,000 per QALY. The practical implication is that we should not implant ICDs in patients with less than a three-year life expectancy, though obviously some will die as a result of an arrhythmia otherwise preventable with the ICD.

24. Here I am endorsing the fine work of Peter Ubel in *Pricing Life: Why It's Time for Health Care Rationing* (Cambridge, Mass.: MIT Press, 2000).

25. S. Heuser, "Medicare to Pay for Heart Test," *Boston Globe*, March 22, 2006. See also D.M. Bloomfield et al., "Microvolt T-Wave Alternans and the Risk of Death or Sustained Ventricular Arrhythmias in Patients with Left Ventricular Dysfunction," *Journal of the American College of Cardiology* 47 (2006): 456-63. This work was brought to my attention by my second-year medical students as part of their Integrative Exercise policy paper. My thanks to Charles Carter, Tim Haffey, Rich Hall, Nick Kuhl, Linda Murray, Shrishail Nashi, Ho-Jin Ra, Angela Spry, and Ebon Wallace-Talifarro.

26. E. Nadler, B. Eckert, and P. Neumann, "Do Oncologists Believe New Cancer Drugs Offer Good Value?" *The Oncologist* 11 (2006): 90-95.

27. L.M. Fleck, "Last Chance Therapies: Can a Just and Caring Society Do Health Care Rationing When Life Itself Is at Stake?" *Yale Journal of Health Policy, Law, and Ethics* 2 (2002): 255-98. See also my essay "Just Caring: Oregon, Health Care Rationing, and Informed Democratic Deliberation," *Journal of Medicine and Philosophy* 19 (1994): 367-88.

28. To iterate, the very opposite of a "properly managed" conversation is one that has been surreptitiously manipulated by pharmaceutical companies, as has happened in the United Kingdom with the Herceptin issue (see ref. 13 above). My thanks to my partner, Jean Edmunds, for her skillful researching of British sources.

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Special Paper

Advocacy and Activism: Missing Pieces in the Quest to Improve End-of-life Care

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ABSTRACT

Increasing attention has focused on end-of-life care and has identified significant deficiencies in access and quality of care. When problems with quality or access to care have been identified for other diseases or conditions, the public has often responded vigorously. This paper describes two kinds of public action that have been effective in improving health care in other areas: advocacy and activism. However, a public response to improve end-of-life care has been muted. We discuss some of the reasons for this lack of response, and propose ways in which providers and funding agencies can work with patients and their families to improve end-of-life care.

INTRODUCTION

IT HAS BECOME APPARENT in recent years that end-of-life care in the United States suffers from serious deficiencies. Since the Institute of Medicine's influential report identified end-of-life care as a problem and a priority[1] numerous studies have added to a list of shortcomings in care for dying people in this country.[2–4] These data paint a grim picture of care at life's end that is characterized by poor quality and inadequate access to valuable services.

When serious flaws have been found in other aspects of health care, the public response has often been swift, loud, and effective. One early example of a powerful public reaction occurred with the introduction of hemodialysis for treatment of end-stage renal disease. When the public realized that access to this potentially life-saving treatment was limited, the result was a general outcry, intense lobbying, and federally funded access for all who needed it.[5,6] Since then, the public has mobilized in support of acquired immune deficiency syndrome (AIDS) research and treatment, breast cancer research funding, and against so-called "drive-by deliveries" in obstetrics. In all of these areas, public action expanded access to desired services and research, and raised standards for care.

Given the prevalence and severity of the deficiencies in end-of-life care, it is somewhat surprising that there has not been a similar groundswell of public interest and action in this area as well. End-of-life care has near-universal significance because most people will die after a period of illness or disability, and therefore everyone stands to gain from improvements to the current system of care. Moreover, most people will become caregivers for dying family or friends. In both of these ways, everyone is a stake-

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holder who is likely to benefit from improvements in end-of-life care.

In this paper, we outline the ways in which public action would help to rapidly and substantively improve end-of-life care. We focus on two kinds of public action: advocacy to improve the care of oneself or a family member, and activism to improve care for a group. We discuss some of the opportunities for advocacy and activism in end-of-life care, and we outline some of the barriers that exist. We conclude by suggesting ways that health care providers can align themselves with constructive public action to achieve urgently needed improvements in access and quality of care.

CURRENT PROBLEMS WITH ACCESS AND QUALITY

Deficiencies in the current system of end-of-life care are severe and pervasive (Table 1). Broadly, these deficiencies can be described as problems with quality of care and problems with access to care. Problems with quality of care are numerous, and include an unacceptably high prevalence of pain and other symptoms[3,4,7] and a paucity of social and emotional support services for dying patients and their families.[8]

Obstacles to access are equally troubling, and reflect system-wide problems with the way that end-of-life care is funded and delivered.[9–11] Chief among these is the "either-or" dichotomy that forces patients and their providers to choose between life-prolonging and palliative modes of care, when concurrent interventions of life-prolonging and palliative intention are often clinically indicated. This dichotomy is imposed and epitomized by the current hospice payment system that requires a prognosis of 6 months or less for eligibility. This criterion effectively restricts access to those with a limited life expectancy. When combined with the threat of legal sanctions and stiff fines for incorrect prediction of survival, it creates a strong deterrent to timely referral.[12,13] Overall, the result has been that patients may not have access to hospice until late in their illness.[14]

TABLE 1. CURRENT PROBLEMS WITH END-OF-LIFE CARE

1. Inadequate training for providers (e.g., training in attitudes, knowledge, and skills)
2. Failure to measure important indicators of quality care (e.g., pain management)
3. Organizational barriers to end-of-life care (e.g., poor continuity of care)
4. Financial/payment barriers (e.g., 6-month hospice requirement)
5. Legal barriers (e.g., triplicate prescriptions)
6. Inadequate research/evidence to guide practice

Despite these deficiencies in end-of-life care, public demands for improvement have been muted. For instance, there are no general movements or broad-based coalitions to improve end-of-life care as there are to improve care for diseases such as AIDS, breast cancer or Alzheimer's disease. End-of-life care also lacks public education programs to create informed consumers as there have been in obstetrics, and coalitions that lobby for increased funding as there are for AIDS and other diseases.

This is not to say that public involvement in end-of-life care has been entirely absent. The public has played a role in nonprofit organizations such as Choice In Dying and Americans for Better Care of the Dying, Partnership for Caring, and the Robert Wood Johnson Foundation's Last Acts campaign are attempting to build public support through public education and community initiatives.

Examples of activism include education programs for legislative staff and Washington, D.C.-based staff of professional health associations and Congressional policy briefings and testimony, meetings with regulators regarding issues of access, quality and costs of needed goods and services. A recent flurry of work at a regulatory level has occurred in response to the media attention and law enforcement efforts occasioned by deaths attributed to Oxycontin™ (Purdue Pharma, Stamford, CT). Leadership of the organizations mentioned and other nonprofit organizations have been working with the Drug Enforcement Agency regarding problems of drug diversion while emphasizing the need to ensure proper treatment of people in pain and the need to ensure availability of opioids to patients for whom they have been properly prescribed, particularly in underserved, poor neighborhoods. Consumer advocacy tools have been developed and are being disseminated to assist people with issues of access and quality of care. These include the Patients' Bill of Rights, legally valid user-friendly advance directive forms, answers to "frequently asked questions," pain scales (for various ages and abilities), symptom journals, tips for choosing hospitals, home health and hospice programs,

assisted living facilities and nursing homes, and tips for talking with doctors about symptoms and preference for care. All of these efforts are valuable, representing early attempts to build community interest and involvement. They are not outgrowths of public involvement as much as they are attempts to develop this involvement.

Perhaps the single clear exception to this pattern of public apathy and inaction has been in the movement to legalize physician-assisted suicide. This highly charged discussion has been the epitome of public involvement, with instructional websites, lobbying, and a proliferation of grassroots organizations. This issue has sparked the public imagination, and has motivated broad-based public action. However, this action is unlikely to result in substantial improvements in end-of-life care because it has been narrowly focused on rights of privacy and freedom from public restraints, not on improving care. Although the assisted suicide debate may be viewed as a response to deficiencies related to end-of-life care, it is an oblique response that has not fostered constructive changes in health care policy and practice.

Therefore, if public action is to be effective in improving end-of-life care, it must target existing deficiencies directly. Opportunities to do so exist at two levels. First, individuals can press for improved access to and quality of care for themselves and their family members. That is, they can be advocates for their "family" of relatives and close friends. Second, individuals can act in ways that collectively advance goals of expanded access to and quality of services. In doing so they become activists. Below we discuss advocacy and activism, and the opportunities and obstacles that exist for each.

INDIVIDUAL AND FAMILY ADVOCACY

Advocacy is essential to improving end-of-life care because involvement at this level can most directly affect providers' behavior. Patients and their families should expect—and be prepared to demand—that providers will elicit and respect preferences for end-of-life care, that they will manage pain and other symptoms effectively, and that they will follow patients throughout the course of their illness. In fact, limited evidence suggests that patients and their families can receive better end-of-life care if they are educated and if their expectations for care are raised.[15] Furthermore, if enough patients share these expectations, it is reasonable to expect a shift in the standards that clinicians set for themselves, and their expectations of the institutions and health plans with which they work.

In other areas of clinical practice, patients and their families have shown that advocacy can be remarkably successful in changing provider practices. One of the most impressive examples comes from the field of obstetrics. In a relatively short time, an educated consumer population, armed with new expectations, reshaped the way that medicine approaches pregnancy and childbirth. Prenatal and delivery care have been transformed from a physician-directed set of encounters to a collaborative process in which women and couples act in partnership with their physicians and increasingly, with midwives.[16] Much of this progress was won by individuals who came to their providers as advocates, and clearly expressed their expectations for care.

Similar gains have been achieved by caregivers on behalf of others. For instance, parents of children with disabilities often become quite knowledgeable about their children's care and come to clinical encounters with demands for expertise from physicians. Similarly, the caregivers of patient with Alzheimer's disease may become advocates on behalf of parents or spouses affected.[17,18]

The exhortation to become an advocate for one's own health care and the health care of loved ones is hardly new, and bookstores offer a comprehensive selection of self-help books devoted to an infinite array of health-related topics. Recently, the ranks of these publications have grown to include comprehensive guides to end-of-life care as well.[19] However, a similar degree of advocacy may be difficult in the setting of end-of-life care because public expectations are remarkably low. Indeed, data suggest that patients and their families may be quite satisfied with care that fails to provide basic symptom relief.[3,20,21] But when patients and families lack benchmarks of "a good death," it may be very difficult for them to recognize deficiencies in their own care. Therefore, several complementary strategies will be required to encourage effective advocacy by patients and their families (Table 2).

First, accounts of "good deaths" are necessary to serve as benchmarks in order to raise expectations. These accounts can be disseminated to pa-

TABLE 2. OPPORTUNITIES TO INCREASE ADVOCACY AND ACTIVISM

Advocacy
Stories of "good deaths" to raise expectations
Patient bills of rights
Standards for care widely available to potential patients
Measures of quality end-of-life care as "report cards"
Litigation in select cases
Activism
Enhance expectations for care in related areas (e.g., pain management)
Enlist disease-based voluntary health associations to:
Raise awareness
Enhance expectations of members
Gather data about members' experience and goals
Participate in coordinated political action

tients and their families through patient educational materials, and through the media. It is important to note that no single "good death" can serve as a template. Instead, ideas about what constitutes a good death are likely to be complex and diverse. Even if common themes inform perceptions of a good death, such as dignity, control, or a chance to help others,[22,23] these qualities will be understood in different ways, and weighted differently by different people. Therefore, the accounts of good deaths that are disseminated should be diverse as well. A realistic goal is to disseminate a variety of diverse accounts, in which all patients can find examples of what a good death would be for them.

These accounts of a variety of good deaths can be used as the background for a well-crafted patients' "bill of rights" that can anchor demands for better end-of-life care. These demands need not create an antagonistic relationship between patient and physician. Indeed, these are not necessarily demands that patients should make of their physicians. Instead, these are expectations that patients and physicians should have of the health care system.

To encourage and support effective advocacy, standards for care should be made available in print and recorded media formats as well as on Internet websites of respected, nonprofit watchdog organizations and those standards should be applied to create "report cards" that are easily understandable and readily accessible. These standards can serve as guides to physicians and families who may be uncertain whether a patient is receiving optimal care.[24] Tools like these can also exert pressure on the health care system if they help physicians, patients and their families to choose institutions and health plans based on their ability to facilitate excellent end-of-life care.

Patients and their families should also be aware of legal means for improving care.[25] Lawsuits can be an important force in improving end-of-life care because they effect change on a scale that would otherwise require the advocacy efforts of many individuals. In this respect, lawsuits can be considered as an important tool of both advocacy as well as activism (discussed below). In obstetrics, lawsuits pursued by patients with the support of physicians and medical professional associations proved to be a powerful force in curtailing 24-hour length of stays for deliveries. Of note, lawsuits have also been influential in establishing the right to refuse treatment.[26,27] Many of the later cases have focused on refusing life-sustaining treatment near the end of life both by patients,[28,29] and by others on patients' behalf.[30,31]

This is a broad set of goals, and will require the dissemination of information that must be accurate, up-to-date, and consistent. A variety of agencies and institutions will have roles to play. Initially, however, public funding agencies and private foundations can be instrumental in developing basic resources to enable people to become informed consumers and effective advocates. Funding is needed for demonstration projects that promulgate standards for care, creation of patient bills of rights, and report cards and that disseminate diverse narratives of good deaths.

SOCIAL ACTIVISM

Advocacy by individuals can directly improve care for a patient. However, organized public participation, or activism, is required to alter institutional and professional policies, curricula and standards of care. The individuals who are involved in activism may be patients and their families. However, patient and family involvement is activism rather than advocacy if improving care for groups of patients, or systems of care is a goal.

Sometimes actions can have both advocacy and activism as concomitant goals. Although most lawsuits are intended to improve care for a single patient, or more often to redress wrongs that occurred in the course of that patient's care, they also have the potential to improve access and

quality of care for large groups. For instance, the media coverage of lawsuits that seek damages for inadequate pain and symptom management can focus local attention on end-of-life care. Specifically, these lawsuits can increase clinicians' and institutions' awareness of end-of-life care as a problem and a priority. Litigation can also exert pressure on hospitals and insurance carriers to raise standards for care. Although they should be used judiciously, there is a potentially important role for litigation as part of a broad campaign of public action.

Opportunities for activism are numerous. Indeed, much of the current crisis in end-of-life care is attributable to system flaws that must be addressed through organized public and consumer action and legislation.[32] Carefully structured and vigorous public efforts will be required in a variety of specific arenas. For instance, there is general agreement that fundamental changes in hospice eligibility criteria are needed,[9,10,33] as are global standards for reimbursement for end-of-life care,[34] and Medicare waivers for palliative care demonstrations.[11] Legal protection for physicians who prescribe high doses of opioids will also be essential to improving end-of-life care.[35] In addition, federal funds are needed for research to improve end-of-life care and new modes of reimbursement and financing that replace the dichotomous either-or model with a needs-based approach that foster a continuum of life-prolonging and palliative care. Public watchdog organizations would also provide a valuable service by monitoring quality and access to specialized end-of-life care.

In other health-related areas, activists have been remarkably successful in using consumer power and legislation to achieve similar goals. This lesson has been most vividly illustrated by the history of AIDS research and treatment. Coalitions of AIDS activists were able to accomplish far more than a single group could have. For instance, the creation of funding programs such as the Ryan White CARE Act was the product of a formidable collaboration between the gay community and the hemophilia community, and included both patients and their families. Activism directed at human immunodeficiency virus (HIV) drug testing and approval, on the other hand, called for aggressive tactics for which the gay community proved well-prepared.[36,37] In a short time, community activism accomplished astonishing legislative changes in funding for HIV care and pressured the Food and Drug Administration (FDA) to streamline the process of approval of potentially valuable medications.

Another example of successful activism can be found in the recent history of obstetrics. In addition to individual advocacy by patients described above, efforts to change the policies of health plans also included substantial political pressure that was brought to bear on managed care organizations.[38] In a number of states this resulted in unprecedented legislation mandating minimum postpartum stays.[39] Overall, these changes illustrate the power of educated and organized individuals acting together to effect social change.

Activism directed toward improving end-of-life care may prove more difficult to organize and advance. Patients and their families face at least four obstacles in becoming effective activists for better end-of-life care. First, the very nature of illness places caregivers and patients at high risk of symptoms and stress that disable them from taking vigorous action. Second, most patients are not part of a cohesive community that is accustomed to political action. Third, voluntary health organizations, which are natural nexuses for patient and family activism, may be reluctant to promote end-of-life care, feeling that acknowledging death may be counterproductive to raising money needed for research into life-prolonging treatments. Fourth, any efforts to generate activism will likely encounter cultural avoidance and denial of dying and death. We examine each of these obstacles, and potential constructive responses to them below.

The first obstacle is a paradox of sorts. Those patients who suffer the greatest burden of symptoms and inadequate care are the patients who have the most to gain by becoming activists. But they are also the least able to do so if they are burdened with severe symptoms. The same constraints trap the families of seriously ill and dying patients. These family members are often full-time caregivers and face demands on their psychological and physical health, their time, and their finances.[40–42] Studies of caregivers have revealed the often overwhelming responsibilities that families shoulder and the substantial burden of unmet needs many families suffer.[8,43,44] For these reasons, patients with severe symptoms and caregivers who are heavily burdened have the most to gain by improving the health care system. However, they have the most difficulty doing so.

To overcome these obstacles and build a broad base of activism, it will be necessary to enhance people's expectations for pain and symptom management in a variety of different care settings. For instance, all patients should expect adequate pain and symptom management during routine surgery and in the outpatient clinic. In having such expectations, knowing what to ask for—and when to complain—each of these settings become places in which all patients can exert pressure on the health care system to be more responsive to their needs. Patients who know their rights and have the energy and capability to assert those rights can act as advocates to raise standards of care for themselves. By applying these same expectations to improve conditions and adherence to standards of care, they can also improve the care of others whose capacities for self-advocacy have been sapped by illness. Examples of efforts directed at institutional or system change that qualify as activism include, complaints to local hospital administration, a resident and family petition seeking to improve staffing during nights at a local nursing home, letters to the editor, formal complaints to state or federal regulatory authorities, or a law suit seeking damages arising from inadequate staffing or care. In addition, future caregivers can also become activists before they are burdened excessively. For instance, individuals can think now about the challenges that they will face when their parents age, and can support demonstration programs such as Medicaring,[11] or legislation to improve care in nursing homes.

Potential activists for end-of-life care face a second obstacle. A sense of a mission-driven community is a crucial catalyst for activism. The lack of a shared disease-specific experience may make it difficult for activists in end-of-life care to emulate strategies that proved successful in AIDS, end stage renal disease, Alzheimer's disease and breast cancer. Furthermore, it may be very difficult for patients and their families to think about, and to plan for, care around the time of death. All patients would benefit from improvements to end-of-life care, but this common purpose may not always be obvious, or easy to accept. Until there is general recognition that better end-of-life care should be a common goal, the strategies of AIDS patients or breast cancer survivors may be difficult to adopt. For activism to be successful in improving end-of-life care, it will be necessary to build a recognition of shared goals and an acknowledgment that end-of-life care should be a priority.

An important strategy to achieve this goal will be to enlist the support of disease-based voluntary health associations such as the American Cancer Society, the Candlelighters Childhood Cancer Foundation, the Treatment Action Group for AIDS, the Susan G. Komen Foundation for breast cancer survivors, the National Cancer Survivorship Coalition, the National Family Caregivers Association, or the National Association of People with AIDS. These groups can be ideal starting points for building a broad-based collaborative program of social activism because they represent people affected by potentially life-limiting illness and because they have structures in place and lines of communication open. Moreover, these organizations are already active in professional and public policy arenas and many have memberships that are committed to public activism.

However, within this strategy lies the third obstacle to activism. Although voluntary health associations are essential to improving end-of-life care, they may be reluctant to take on this issue. Much of these associations' existing research and fund raising is built on hope for a cure, and attention to dying may be perceived as a dilution of focus. Worse, it may be viewed as an admission of defeat. Consequently, it is possible that voluntary health associations will see attention to end-of-life care as potentially damaging to their organizational image and fund development. To counter this concern and avoid unintended negative effects of collective action to improve end-of-life care, it will be necessary to create positive, hopeful messages that can be used to recruit voluntary health associations and their members. At least initially, these messages should emphasize goals that are less threatening, such as assistance for burdened caregivers, and better pain and symptom management.

To enlist the support of these associations, grant support from public agencies or private institutions will be essential. Support can encourage associations to act in three areas. First, funding can support these groups in gathering information through membership surveys and focus groups about members' needs and priorities. Second, funding can help disease-specific voluntary health associations and patient groups to raise awareness of end-of-life issues and expectations of care among their members through

education and Internet-based communication. Finally, funding can help disease groups to organize activist efforts in productive directions, such as letter-writing campaigns, media events or direct legislative lobbying.

The sense of denial and fear that characterize public reactions to discussions of death and dying is a fourth obstacle to social activism. This barrier is far more insidious and pervasive than those described above, and may prove to be far more resistant to change. An extensive literature on the communication of risk has demonstrated that public messages fail to generate public interest or alter behavior if the people do not perceive that they are at risk.[45,46] This is true of virtually every public health risk and intervention that has been studied. Denial of death, and a reluctance to think about the implications of poor end-of-life care for oneself and one's family, may represent a significant impediment to generating effective activism.

Although not easily overcome, research on risk communication has identified key strategies that have proven useful in other settings.[47] Media may play a critical role in what is known as the social amplification of risk.[48] That is, the media can increase the likelihood that an event will have an impact on public opinion by highlighting certain aspects of that event, such as its involuntary or inescapable nature, its impact on identifiable individuals, or the inequitable distribution of its consequences. In other settings, these are features of events that have been termed "fright factors," and that have been used successfully to increase awareness about health hazards.[49]

THE ROLE FOR CLINICIANS IN ADVOCACY AND ACTIVISM

Advocacy and activism need not be left to patients and families alone. Professional caregivers may initially react defensively to advocacy and activism as intrusions on their professional authority, but clinicians are stakeholders in the health care system and have an inherent interest in improving end-of-life care. In fact, professional organizations have been active in addressing acknowledged deficiencies through programs such as the American Medical Association's Educating Physicians in End of Life Care (EPEC) training, and physicians have an important role to play in activism generally.[50]

Advocacy and activism should not be viewed as a struggle between patients and clinicians. Instead, effective advocacy is the result of a partnership among clinicians, patients, and their families. Effective social change is facilitated through collaborative action among stakeholder constituents.

Clinicians can take the lead in forging such an alliance because they retain the trust of patients and their families to a degree that even the most respected organizations cannot hope to match. This trust places clinicians in a unique position to serve as catalysts for both advocacy and activism. Most importantly, clinicians can contribute to change by adhering to standards of care that meet or exceed patients' and families' expectations. Clinicians' training and the health systems within which they work should enable them to promise patients that intolerable suffering will not mark their final days and that the care they receive will be consistent with their preferences. Clinicians can describe "good deaths" as points of reference, helping patients and their families imagine what is possible in the way of positive outcomes despite unwanted circumstances.[23,51] Simultaneously, providers can engage in professional activities that raise expectations among colleagues. And, in leading by example, they can raise expectations within local institutions and health systems and professional communities. Health care providers can be active in this manner as individuals, as group practices and as members of professional associations that establish formal standards of care. Clinicians can also help patients and families to identify ways in which their goals were not met. Specifically, clinicians will know when an insurance company's refusal of a desired palliative treatment—perhaps an expensive parenteral antiemetic medication or hospital admission for pain management—or support service is unreasonable. They also know when a nursing home will not accept a patient for respite care or when a Medicare fiscal intermediary rejects certification of an additional Medical Hospice Benefit period, forcing a patient to be discharged from a hospice program on which the patient and family have relied for complex care needs. Examples of these sorts represent important failures of the current system of care at the end of life. They also represent potential points of leverage at which patients or their families can become advocates and activists for better end-of-life care.

Clinicians are well positioned to contribute raw material needed for activism by collecting stories. Both positive accounts of excellent end-of-life care and satisfying life closure and tragic stories of care gone awry and needless suffering are valuable. The history of activism in these and other areas has demonstrated that stories have the potential to motivate the public in ways that numbers cannot. Stories have the potential to change policy and practice in ways that statistics alone cannot. Indeed, what attracted the public's attention and support for the Ryan White AIDS CARE Act was not data regarding insurance coverage among HIV-infected people, but rather the story of a family that could not afford prohibitively expensive medications.[52] Similarly, it was the story of a hemodialysis patient, told directly to Congress, which laid the foundation for the Medicare End Stage Renal Disease program.[5] These precedents suggest that clinicians can also use the stories of real patients to motivate change in end-of-life care.

CONCLUSION

The strategies described here for advocacy and activism can be complementary and synergistic forces in improving end-of-life care. At one level, as advocates, patients, and families can have direct and immediate impact, driving change much more quickly than "top-down" regulation or professional certification and quality improvement efforts. This is particularly true if advocacy is fueled by achievable expectations, and facilitated by practical consumer tools, such as relevant patients' bill of rights and health care report cards.

But "top-down" professional and health systems initiatives are also essential, and their success or failure will ultimately shape the environment in which advocacy takes place. Advocacy can only be effective if patients and their families recognize inadequacies and if they have the information and tools needed to effect change. Large-scale public education initiatives, widely accessible and understandable quality indices, and clearly defined avenues for complaints and recourse are all needed. All of these will require significant commitments and energetic efforts directed at social change. These efforts will also require ongoing evaluation to assess their effectiveness in changing public perceptions, behavior or both.

Substantial, lasting improvements in end-of-life care will require a combination of advocacy and activism built on a foundation of data and stories. These efforts to expand access and improve the quality of valued services will require the commitment of individuals, clinicians, and disease groups and the support of funding agencies. Establishing this foundation will not be easy, in part because of the obstacles described above. However, as professionals, as members of families, and as individuals who will inevitably face life's end, we all have an important stake in making sure these goals are met and ample reasons to invest the time and energy required to achieve these critical goals.

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TESTIMONY OF GORDON H. SMITH, ESQ., EXECUTIVE VICE PRESIDENT, MAINE MEDICAL ASSOCIATION TO THE JOINT STANDING COMMITTEE ON APPROPRIATIONS AND FINANCIAL AFFAIRS, FEB 22, 2007 RE L.D. 499 (GOVERNOR'S BUDGET)

Sen. Rotundo, Rep. Fischer and members of the Committee:

Thank you for the opportunity to testify today on behalf of the 2700 members of the Maine Medical Association, a professional association representing the interests of Maine's physicians. We are here today to support the provision in the budget in the so-called MAP account that would appropriate an additional $3 million in the second year of the biennium to increase MaineCare payment rates for physicians and other providers who bill for MaineCare services pursuant to the fee schedule, as opposed to being paid on the basis of their costs.

This increase, although modest in the context of a $2 billion annual MaineCare budget, is essential in order to provide access to medical care for the more than 260,000 children and adults who rely on the MaineCare program. With federal matching funds, this appropriation will allow for changes to the fee schedule that will increase reimbursement by approximately $8.5 million. We anticipate that the increase would move most MaineCare fees from 53% of the Medicare fee schedule to approximately 60%. While Maine would continue to have among the lowest fees in the country (we were 44th in 2001), this "down payment" would demonstrate to Maine's physicians and other providers that the state is making an effort to recognize their daily efforts to provide access to MaineCare patients.

As you have heard previously, Maine has the largest number of Medicaid patients, per capita, in the country. The combination of low fees and large numbers of enrollees, along with the MECMS problem and other administrative issues has greatly challenged the medical community in Maine. Perhaps the best evidence of this is the exodus of physicians from private practice, where the state pays the lowest fees, to employment. Over 1300 physicians are now employed in hospitals, not including health centers and other settings.

The last increase was in 2005 and also was $3 million. How this increase was applied is attached to my testimony. As you can see, many of the specialties received very, very modest increases, as the goal was to have a minimum payment for any code correlating to 53% of Medicare. Why 53% you might ask – simply because that is as far as the money would take us.

Physician fees in MaineCare represent less than 3% of MaineCare expenditures. Physician fees are certainly not a cost driver in the system. A modest increase can help

ensure appropriate access and help cover the cost of providing the care, costs which, of course, increase every year.

While we are disappointed that the increase would not take effect until July of 2008, it is important to at least do this much to show support for the decreasing number of physicians left in private practice and for those institutions who employ physicians who still are paid from the private fee schedule. Two of these larger systems are Maine Health and Maine General, neither of which have elected to convert their physician practices to "provider-based" reimbursement.

In the interest of time, I will not go through the appendices attached to my written testimony which give comparisons between MaineCare, Medicare and commercial insurance rates for a number of frequently billed codes. I have also attached a November, 2006 article from American Medical News which sets forth the expectations of a number of other states regarding plans for Medicaid reimbursement.

In terms of how Maine compares with other states, I will share with you the results of a recent inquiry on our state medical society CEO list serve related to Medicaid reimbursement. Most states responding noted Medicaid reimbursement rates ranging from 70% of Medicare to 100% of Medicare. I saw no state as low as 53% and firmly believe that we have about the lowest reimbursement in the country, and perhaps the lowest. This modest increase, even if delayed by a year, is long over due and essential.

There are many other arguments that could be made, including the real financial harm suffered by MaineCare providers as a result of the claims processing issue, but I believe that you are all well aware of that.

I would be happy to answer any questions that you may have.

Fee Schedule comparison--MaineCare 2007

HCPCS		2007 Transitioned Non-facility Total RVU	2007 MaineCare	2007 Medicare--loc 3 (York, Cumberland County)	2007 Medicare--loc 99 (Rest of Maine)	% Difference (loc 3)	% Difference (loc 99)	Anthem 07/06 (49.30 CF)
99213	Office/outpatient visit, est	1.66	28.94	59.45	56.03	48.68%	51.65%	81.84
99212	Office/outpatient visit, est	1.02	19.85	36.62	34.02	54.21%	58.35%	50.29
99214	Office/outpatient visit, est	2.52	42.50	90.04	84.99	47.20%	50.01%	124.24
93000	Electrocardiogram, complete	.67	19.18	24.46	22.20	78.41%	86.40%	33.03
99211	Office/outpatient visit, est	.55	13.17	20.14	18.36	65.39%	71.73%	27.12
99215	Office/outpatient visit, est	3.42	60.38	121.61	115.16	49.65%	52.43%	168.61
99203	Office/outpatient visit, new	2.56	48.45	91.41	85.98	53.00%	56.35%	126.21
90772	Injection, sc/im	.53	9.06	19.37	17.69	46.77%	51.22%	26.13
99202	Office/outpatient visit, new	1.73	32.56	61.87	58.02	52.63%	56.12%	85.29
95115	Immunotherapy, one injection	.37	7.29	13.92	12.24	52.37%	59.56%	18.24
69210	Remove impacted ear wax	1.27	24.25	45.47	42.54	53.33%	57.01%	62.61
95165	Antigen therapy services	.28	4.76	10.20	9.19	46.67%	51.80%	13.80
99204	Office/outpatient visit, new	3.92	68.76	138.94	131.72	49.49%	52.20%	193.26
20610	Drain/inject, joint/bursa	1.88	34.28	67.18	62.46	51.03%	54.88%	92.68
17000	Destroy benign/premal lesion	1.73	29.93	63.44	58.24	47.18%	51.39%	85.29
99308	Nursing fac care, subseq	1.49	28.60	52.35	50.18	54.63%	56.99%	73.46
11641	Removal of skin lesion	5.46	99.91	198.38	183.08	50.36%	54.57%	269.18

Virginia

E/M Fee Analysis

CPT Code	Medicare	Carrier A	Carrier B	Carrier C	Carrier D	Carrier E	STATE (Manual)	ANTHEM
New Pt.								-
99201	34.01 33.01	51.25/45.50	40.04	40.00		44.00	21.92	49.73
99202	59.58 58.02	91.00/81.00	71.28	72.00	71.67	78.00	32.56	88.19
99203	88.14 85.98	135.25/120.25	105.82	107.00	106.37	116.00	48.45	131.25
99204	134.58 131.72	191.25/170.25	149.82	152.00	150.91	165.00	68.76	185.60
99205	169.10 165.72	243.00/216.25	190.30	193.00		209.00	87.34	235.85
Est. Pt.								
99211	19.11 18.36	30.00/26.75	23.54	24.00	23.46	26.00	13.17	29.22
99212	35.08 34.02	54.00/48.00	42.24	42.00	41.94	46.00	19.85	52.30
99213	57.45 56.03	73.50/65.50	57.64	58.00	58.44	63.00	28.94	71.27
99214	87.07 84.99	115.25/102.50	90.20	91.00	94.54	99.00	42.50	111.76
99215	117.78 115.16	167.50/149.00	131.12	133.00	133.09	145.00	60.38	162.53
OP Consults								
99241	46.26 45.02	70.25/62.50	55.00	55.00			27.76	68.19
99242	85.50 83.52	128.50/114.25	100.54	101.00		110.00	45.95	124.59
99243	117.19 114.57	171.25/152.50	134.20	135.00		147.00	61.28	166.00
99244	172.93 169.40	241.50/215.00	189.20	191.00		208.00	86.70	234.31
99245	214.40 210.10	312.25/278.00	244.64	248.00			112.32	303.01
IP Consults								
99354	88.40			111.00				
99355	87.83			110.00				
99356	81.29			102.00				
99357	81.51			102.00				

Primary Care office

2005

MAINECARE RATE ANALYSIS: PROJECTION TO INCREASE FEES TO 53% OF 2005 MEDICARE FEE
Claims Data from SFY04 based on Service Date (7/1/2003-6/30/2004) [1]

SPECIALTY	Charged Amount	MaineCare Line Paid SFY04 [2]	Estimate of Medicare Payment [3]	Estimated MaineCare Paid at 53% Medicare [4]	Estimated Additional Dollars Required	Percent Increase	Number of Providers	Number of Procedures Billed	Number of Procedures Increased	Percent of Procedures Receiving Increase
ALLERGY	$102,459	$39,755	$68,164	$43,356	$3,601	9%	2	24	10	42%
CARDIOLOGY	$5,421,161	$1,532,296	$3,448,362	$2,134,058	$601,761	39%	78	232	88	38%
CARDIOVASCULAR SURGERY	$2,330,827	$706,230	$1,333,323	$837,877	$131,647	19%	16	213	97	46%
COLORECTAL SURGERY	$278,683	$52,376	$141,659	$80,287	$27,911	53%	5	92	59	64%
DENTAL	$96,716	$33,146	$69,076	$40,400	$7,254	22%	6	79	44	56%
DERMATOLOGY	$425,685	$111,956	$249,240	$138,546	$26,590	24%	15	77	55	71%
EMERGENCY MEDICINE	$1,745,473	$478,776	$1,049,266	$595,616	$116,841	24%	113	307	137	45%
ENDOCRINOLOGY	$364,009	$100,200	$187,223	$106,488	$6,288	6%	8	77	29	38%
FAMILY PRACTICE	$21,957,466	$8,267,042	$13,859,094	$8,686,750	$419,707	5%	635	1052	480	46%
GASTROENTEROLOGY	$2,301,172	$712,115	$1,192,595	$735,981	$23,866	3%	28	142	52	37%
HEMATOLOGY	$254,575	$128,090	$228,830	$148,888	$20,798	16%	10	46	20	43%
INTERNAL MEDICINE	$10,921,327	$3,693,567	$6,882,164	$4,173,319	$479,752	13%	399	897	374	42%
NEPHROLOGY	$546,562	$196,677	$271,397	$203,039	$6,362	3%	29	102	36	35%
NEUROLOGICAL SURGERY	$5,747,262	$992,185	$1,382,416	$1,055,673	$63,488	6%	24	242	129	53%
NEUROLOGY	$4,247,622	$1,608,812	$3,318,441	$1,973,739	$364,928	23%	49	235	100	43%
OBSTETRICS AND GYNECOLOGY	$22,256,816	$6,174,469	$10,245,822	$6,683,376	$508,906	8%	146	553	279	50%
OCCUPATIONAL MEDICINE	$110,013	$23,321	$48,903	$27,077	$3,755	16%	3	34	15	44%
ONCOLOGY	$1,086,680	$287,781	$681,994	$393,146	$105,365	37%	16	93	42	45%
OPTHAM./OTOLARYN./OTORHIN.	$4,578,751	$1,117,445	$2,261,255	$1,312,497	$195,051	17%	38	383	262	68%
OPTHAMOLOGY	$4,555,150	$1,236,846	$2,214,822	$1,390,650	$153,804	12%	79	341	209	61%
ORAL SURGERY	$85,915	$17,416	$40,047	$23,432	$6,016	35%	17	69	42	61%
ORTHOPEDIC SURGERY	$13,243,850	$3,061,752	$6,082,220	$3,698,297	$636,545	21%	146	970	655	68%
ORTHOPEDIST	$600,911	$136,194	$248,909	$155,811	$19,617	14%	5	196	108	55%
OSTEOPATHIC MANIPULATIVE TRTMNT.	$534,888	$187,562	$341,730	$203,263	$15,701	8%	12	174	49	28%
PATHOLOGY	$5,328,295	$1,126,361	$2,434,398	$1,353,945	$227,583	20%	71	243	66	27%
PEDIATRIC ALLERGY	$342,130	$124,403	$216,982	$137,217	$12,814	10%	1	43	19	44%
PEDIATRIC CARDIOLOGY	$946,342	$281,791	$1,095,903	$622,377	$340,587	121%	4	87	33	38%
PEDIATRIC NEPHROLOGY	$129,850	$36,858	$70,459	$38,588	$1,730	5%	1	25	12	48%
PEDIATRIC SURGERY	$501,118	$257,493	$663,457	$382,294	$124,801	48%	4	208	115	55%
PEDIATRICS	$19,013,835	$6,714,258	$12,071,702	$7,641,079	$926,821	14%	199	794	365	46%
PHYSICAL MEDICINE AND REHAB.	$1,557,021	$482,008	$881,300	$526,011	$44,003	9%	20	112	39	35%
PLASTIC SURGERY	$374,633	$61,677	$141,251	$79,630	$17,753	29%	6	148	116	78%
PSYCHIATRY	$2,797,232	$1,459,729	$2,340,161	$1,478,141	$18,412	1%	74	83	15	18%
PULMONARY DISEASE	$1,754,481	$604,677	$1,306,859	$737,396	$132,719	22%	36	144	70	49%
REHABILITATION MEDICINE	$128,152	$37,925	$70,287	$41,137	$3,212	8%	2	26	12	46%
RHEUMATOLOGY	$743,062	$252,285	$425,988	$272,456	$20,171	8%	15	137	38	28%
SURGERY	$11,555,764	$2,589,186	$4,685,548	$2,972,287	$383,101	15%	164	1186	697	59%
THORACIC SURGERY	$894,080	$209,399	$373,964	$234,849	$25,451	12%	10	234	142	61%
UROLOGY	$2,110,704	$443,783	$1,040,442	$586,188	$142,406	32%	39	247	133	54%
VASCULAR SURGERY	$525,712	$97,888	$208,305	$122,392	$25,003	26%	8	193	113	59%
TOTALS	**$152,496,385**	**$45,675,430**	**$83,873,958**	**$52,067,554**	**$6,392,124**	**14%**	**2,530**	**3,652**	**2,080**	**57%**

[1] See attached Appendix A for data file construction and parameters.
[2] Represents amount paid at line level of claim. Does not reflect eny co peys or third party liability.
[3] Payment estimated using Medicare 2005 Fee Schedule.
[4] Payment estimated using the greater of 53% of Medicare 2005 fee schedule or current fee.

2005

MAINECARE RATE ANALYSIS: PROJECTION TO INCREASE FEES TO 53% OF 2005 MEDICARE FEE
Claims Data from SFY04 based on Service Date (7/1/2003-6/30/2004) [1]
ANESTHESIA AND RADIOLOGY SERVICES

ANESTHESIA SPECIALTY	Charged Amount	MaineCare Line Paid SFY04 [2]	Estimate of Medicare Payment [3]	Estimated MaineCare Paid at 53% Medicare [4]	Estimated Additional Dollars Required	Percent Increase	Number of Providers	Number of Procedures Billed	Number of Procedures Increased	Percent of Procedures Receiving Increase
Anesthesia E&M [5]	$300,403.70	$75,210.18	$171,526.92	$93,731.47	$18,521.29	25%	69	35	16	46%
Anesthesia Non-E&M [5]	$1,263,930.19	$254,093.55	$517,449.71	$301,695.03	$47,601.48	19%	145	102	60	59%
Anesthesia Services [6]	$9,681,411.61	$1,290,139.92	$2,685,666.88	$1,444,646.34	$154,506.46	12%	198			
ANESTHESIA TOTALS	**$11,245,746**	**$1,619,444**	**$3,374,644**	**$1,840,073**	**$220,629**	**14%**				

RADIOLOGY SPECIALTY	Charged Amount	MaineCare Line Paid SFY04 [2]	Estimate of Medicare Payment [3]	Estimated MaineCare Paid at 53% Medicare [4]	Estimated Additional Dollars Required	Percent Increase	Number of Providers	Number of Procedures Billed	Number of Procedures Increased	Percent of Procedures Receiving Increase
Radiology E&M[5]	$146,583	$40,855	$78,424	$43,804	$2,950	7%	94	25	12	48%
Radiology Non-E&M[5]	$17,877,226	$4,726,020	$9,036,385	$6,036,318	$1,371,336	29%	294	329	179	54%
Radiology Services [7]	$12,216,679	$2,530,369	$4,164,980	$348,858	$363,819	14%	215	334	131	39%
RADIOLOGY TOTALS	**$30,240,488**	**$7,297,244**	**$13,279,788**	**$6,428,980**	**$1,738,104**	**24%**				

GRAND TOTALS	Charged Amount	MaineCare Line Paid SFY04 [2]	Estimate of Medicare Payment [3]	Estimated MaineCare Paid at 53% Medicare [4]	Estimated Additional Dollars Required	Percent Increase
TOTALS FOR E&M PROCEDURES	$60,842,113	$21,826,912	$38,762,123	$22,868,478	$1,041,565	5%
TOTALS FOR NON-E&M PROCEDUR	$91,654,272	$23,848,518	$45,111,835	$29,199,076	$5,350,559	22%
ANESTHESIA TOTALS[4]	$11,245,746	$1,619,444	$3,374,644	$1,840,073	$220,629	24%
RADIOLOGY TOTALS	$30,240,488	$7,297,244	$13,279,788	$6,428,980	$1,738,104	24%
GRAND TOTAL	**$193,982,618**	**$54,592,118**	**$100,528,389**	**$60,336,606**	**$8,350,857**	**15%**

[1] See attached Appendix A for data file construction and parameters.
[2] Represents amount paid at line level of claim. Does not reflect any co pays or third party liability.
[3] Payment estimated using 2005 Fee Schedules.
[4] Payment estimated using the greater of 53% of Medicare 2005 fee schedule or current fee.
[5] These procedures would continue to be paid on the physican fee schedule, not based on anesthesiology or radiology fees.
[6] Fee increase statistics are related to calculated values that include the pricing units and time, not a procedure specific fee. Fee increase at 53% of 2005 CF of $16.96 (Rest of Maine).
[7] Fee increase statistics are related to calculated values that include pricing status, pricing units, modifiers, and percentages of allowed amounts as defined by BMS.

HealthInfoNet

Connecting communities for better health.

Electronic Clinical Information-Sharing…

…The Key To Improved Care, Fewer Medical Errors…And Lower Costs

A Guide to

HealthInfoNet

A new statewide system designed to

- *Improve* the quality of clinical care
- *Reduce* medical errors
- *Identify* potential threats to the public health
- *Reduce* duplication of services
- *Improve* clinical and administrative efficiency and effectiveness
- *Connect* Maine to the nation's emerging information technology system
- *Provide* consumers with access to their personal healthcare information

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Electronic Clinical Information-Sharing…

…The Key To Improved Care, Fewer Medical Errors…And Lower Costs

A growing number of healthcare leaders and others across Maine believe that a coordinated statewide electronic *clinical information-sharing system* holds great promise for improving patient safety and the quality of health care.

Under development since mid-2004, HealthInfoNet will allow Maine hospitals, physicians and other providers to quickly and efficiently share computerized patient-specific clinical information. With access to more information about their patients, caregivers will be able to make more informed and better care decisions. Not only will the system immediately deliver up-to-date clinical information to the site of care, it will eventually allow Maine residents to view a summary of their own health records via an electronic patient "portal."

How Is Clinical Information Shared Today?

While more and more electronic medical records (EMRs) are being implemented in Maine and elsewhere, a great deal of patient information is still maintained in paper records that must be mailed, faxed or hand-delivered from one caregiver to another. Even providers and clinical sites that have office-based EMRs are often unable to share data and patient information due to incompatible software or technical limitations. Studies have shown that the current system is inefficient and can lead to unnecessary and duplicative tests. Medical errors can also occur when caregivers do not have access to complete and current information about their patients.

How Will HealthInfoNet Help?

HealthInfoNet will allow a physician or other provider to use a computer or hand-held electronic device to immediately access (with patient consent) the most current medical information about a patient. Information will be drawn from a number of sources, such as the patient's electronic medical record (EMR) at their doctor's office, recent laboratory results, prescriptions, and diagnostic tests, no matter where the data exists. It will then be immediately arrayed on the caregiver's screen as he or she is treating the patient. When all this information is combined, it will be known as an ***Electronic Health Record or EHR.*** Future plans will allow patients to conveniently access their own EHR to confirm that important information, such as an allergy to medication, is correctly recorded. Costs will be reduced as information-sharing becomes more efficient and the number of duplicative or unnecessary tests and procedures is reduced.

HealthInfoNet is closely coordinated with efforts by individual providers and hospitals to develop their own electronic medical records or EMRs. Close communication is also being maintained with the federal government's Office of the National Coordination of Health Information Technology (ONCHIT), which is stimulating the creation of similar systems throughout the country.

Where Does HealthInfoNet Stand Today?

Thanks to growing support, Maine is now poised to become one of the first states in the nation to establish a statewide electronic clinical information-sharing system.

In 2006 HealthInfoNet transitioned from a *project* overseen by a small steering committee of funders to a new independent statewide nonprofit organization. A highly experienced board of directors (see back page) representing a wide range of diverse interests from across Maine now governs this new organization. Broad participation of stakeholder groups and the independent nature of the organization are intended to allow the organization to build financial support and buy-in that will be needed to rapidly move HealthInfoNet toward statewide implementation by 2010.

HealthInfoNet also has assumed a more important role in Maine's overall strategy for improving health care across the state, as outlined in the State Health Plan that was released by the Governor in early2006.

How Will HealthInfoNet Affect Healthcare Costs?

Over time, HealthInfoNet will reduce the number of unnecessary hospital admissions as well as unnecessary and often-duplicative prescriptions, laboratory tests, diagnostic imaging such as x-rays, CAT scans and MRIs. As physicians and other caregivers have access to more complete and current information about their patients, they will be able to better manage chronic illnesses and make more informed decisions that will reduce medical errors. All of this will contribute to lower costs that should result in more affordable health insurance coverage.

The RAND Corporation estimates that electronic information-sharing could save nearly $42 billion a year nationally; the largest savings would occur from fewer inpatient hospitalizations (approximately $19 billion/year.) A 2004 study estimated that Maine should save approximately $40 million each year as HealthInfoNet is implemented. Even greater savings may be achieved as electronic information-sharing occurs throughout the entire healthcare delivery system. For example, HealthInfoNet estimates that approximately $26 million could be saved annually by eliminating unnecessary or duplicative prescriptions, lab tests and diagnostic imaging such as x-rays, CAT scans and MRIs.

When Will HealthInfoNet Become Operational?

Plans call for the system to be tested in several locations across the state by late 2007. A goal has been set to have the system operating across Maine by 2010. Substantial additional funding will need to be identified in order to accomplish these ambitious goals. Funding is among the HealthInfoNet Board of Directors' highest priorities.

What Kind Of Technology Will HealthInfoNet Use?

Technology system-development has been a priority over the past year in the HealthInfoNet Planning and Development process. Thanks to the work of the HealthInfoNet Technology Committee, made up of nearly 20 experienced chief information officers and physicians, there is now a consensus on the technology architecture needed to build the new system and integrate it with emerging systems across the state and throughout the nation.

(continued on back page)

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The HealthInfoNet system will be built by a national technology company with extensive experience in the development of similar systems. A comprehensive national Request For Information (RFI) and selection process began in mid-2005 and will conclude, with final vendor selection by late 2006. This will allow planning for first stage implementation to begin by early 2007.

How Will Patient Privacy Be Protected?

Today, both Maine and the federal government have stringent laws and regulations that are designed to protect the privacy of patient information. HealthInfoNet will comply with all of these laws. Public opinion surveys show that consumers are supportive of systems such as HealthInfoNet because they understand these systems can lead to improved care. However, the public remains concerned about the privacy and security of their personal medical information as we move from paper-based record keeping to electronic record systems.

In 2005, HealthInfoNet invited approximately one dozen consumer advocacy groups to take part in a series of meetings to explore these issues and develop a set of recommendations for the new HealthInfoNet system. The HealthInfoNet Consumer Stakeholder Group thoroughly reviewed existing state and federal statutes and regulations. The Group then developed a set of recommended principles to guide the development of the system. These principles call for rigorous safeguards to be built into the technology system to insure the highest levels of privacy and security and provisions that would allow legal recourse for consumers who believe their personal information has been inappropriately disclosed. The Group also recommended a public awareness campaign to build understanding of the system. Today, consumer representatives serve on the HealthInfoNet Board of Directors and a new Consumer Advisory Committee will become a permanent element of HealthInfoNet's governance structure beginning in the fall of 2006. Maine currently is one of 34 states taking part in an extensive national initiative designed to identify the best practices for protecting patient privacy.

How Is HealthInfoNet Being Funded?

HealthInfoNet's original funders (Maine Health Access Foundation, the Maine Quality Forum/Dirigo Health Agency, the Maine Center for Disease Control and Prevention, and the Maine Health Information Center) have supported HealthInfoNet since its inception in mid-2004. These four organizations have now been joined by several private foundations, a major payer, a large financial services institution, four of Maine's largest health care provider systems and the federal government. Among key professional organizations that are supporting HealthInfoNet process are the Maine Medical Association, the Maine Osteopathic Association and the Maine Hospital Association.

How Can I Get More Information?

For more information about HealthInfoNet, please visit www.hinfonet.org.