

*Maine Center
for
End-of-Life Care*



A Business Plan

TO: Members of the Legislative Council, 120th Legislature

FROM: Dora Anne Mills, MD, MPH, Director, Bureau of Health, Maine Department of Human Services

DATE: August 29, 2001

The purpose of this memo is to inform you of our implementation of PL 439, Section LL-7 which states:

“The Department of Human Services, Bureau of Health may establish, through contract or otherwise, the Maine Center for End-of-Life-Care. The purpose of the center is to educate health care providers and the public regarding pain management and palliative and end-of-life care.”

After meeting with a number of stakeholders on end-of-life care, including some legislators, it was clear to me that all of them felt the most appropriate place for the Maine Center for End-of-Life Care is the Maine Hospice Council. I am therefore writing to inform you of the creation of the Center within the Maine Hospice Council.

The Bureau of Health, including myself, will assist in any way possible in further establishing this Center. For instance, we have included a request for some funding for the Center in a recent grant application for comprehensive cancer control to the Centers for Disease Control and Prevention. In addition, I am currently serving on a committee that is working to implement all aspects of Maine’s end-of-life care initiative included in PL 439.

Acknowledgments

Special thanks to those individuals and organizations who have made this document possible through their individual and corporate contributions of time and money.

MeHAF *

Hospice Education Institute

Pam Bennett, Senior Director of Advocacy, Purdue Pharma, LP

Mike Fulton, Golan/Harris International

Jayne Sokolow, The Development Source, Inc.

MHC Business Planning Committee

And all other supporters and funders.

* The Maine Health Access Foundation (MeHAF), created in 2000, is the state’s largest health care foundation. Their mission is to promote affordable and timely access to comprehensive, quality health care and to improve the health of every Maine resident. In particular, MeHAF targets strategies that serve the uninsured and medically underserved.

Maine Center for End-of-Life Care

MISSION

To act as an incubator for change, promote innovation, foster community-based collaboration, and serve as an informed convener and educator.

VISION

To create a more socially responsive environment for end-of-life care.

DEDICATION

This business plan is dedicated to the memory of two individuals whose personal courage and tireless efforts toward improving end-of-life care were exemplary.

Joe Mayo, Clerk Emeritus of the House of Representatives

Larry Harcourt, MD

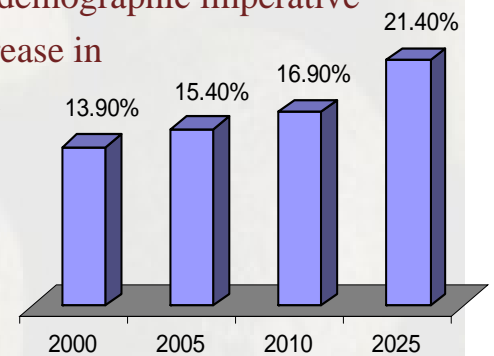
Executive Summary

The development of the Maine Center for End-of-Life Care (Center) is a natural evolutionary step for the Maine Hospice Council (MHC). Since 1984, the MHC has been creating innovative opportunities, fostering collaboration, and serving as a convener and educator for end-of-life issues. Change in attitudes and practice behaviors has been slow in coming; however, the social and demographic imperative to continue is stronger than ever, as demonstrated by the increase in Maine's aging population (see graph) and the Last Acts State Report Card (see insert on opposite page).

Developing partnerships with the goal of building community has been the cornerstone for many successful MHC grants. For example, in 1999, the MHC became the administrative agency for a Community/State Partnership Initiative from the Robert Wood Johnson Foundation (RWJF). The grant entitled, "Care at the End-of-life: A Public Private Partnership", involved fourteen major healthcare and academic partners working on ten projects.

The Maine legislature recognized the importance of addressing end-of-life issues with two pieces of legislation: the first being a bill to assist in funding the operations of the MHC in 1989; the second, a section of PL 439 (passed in 2001) to create the Maine Center for End-of-Life Care.

Since accepting the responsibility to develop the Center, the MHC has taken appropriate steps to initiate implementation. A meeting of stakeholders was convened to determine the need, if any, for an end-of-life center, and to discuss a vision for such an entity.



Maine's Aging Population: residents age 65 and over will increase from 13.9% in 2000 to 21.4% in 2025. In addition, there will be a 40% increase in the number of people over age eighty-five by 2010.

(Mageean, Deidre, et.al., *Wither Maine's Population?*, Maine Policy Review, Winter 2000.)

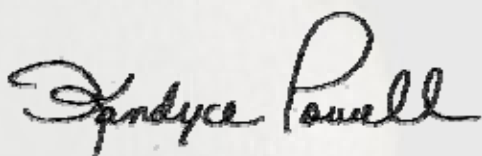
We have found that it is through collaborative efforts such as workshops, educational programs and communication that we most efficiently meet our objectives. The opportunities for additional research, advocacy and education that the Center can provide will help us to meet our mission.

Karen O. Fletcher
Maine Hospital Association

As a result of this meeting, the concept of the Center as an “incubator for change” took shape. Advocacy, community engagement, research, education and clinical practice emerged as priority areas. A Center was identified as both realistic and necessary; however, it was also acknowledged that a thoughtful business plan, considerable financial support, and increased capacity would be absolutely essential. The input from the stakeholders proved to be invaluable. Many of these partners continue to work with the Maine Hospice Council in order to ensure that this concept becomes a reality.

Under the governance of the MHC committee structure, the Center will benefit from 20 years of experience, knowledge and expertise. The dedication, resourcefulness, creativity and hard work of a volunteer board, as well as limited staff, have been responsible for significant growth (12% annual growth since 1990). Additionally, the MHC has been consistent in devoting 82% of budget to innovative program development.

As we know, many gaps remain. The needs of various populations need to be addressed before universal access to quality end-of-life care via a seamless healthcare delivery system becomes reality. Who is responsible? Each one of us! By accepting responsibility as members of the larger community, we can harness the energy necessary to create real social change. The Maine Center for End-of-Life Care will go a long way toward centralizing these important efforts.



Kandyce Powell, Executive Director



Kandyce Powell has served as the Executive Director of the Maine Hospice Council since 1992. Kandyce has been instrumental in developing partnerships to work on end-of-life issues and is a tireless advocate for the underserved.

Maine's Report Card	
Quality of state advance directive laws	A
% residents dying at home	D
% deaths with hospice	E
Median length of stay	D
% hospitals with self-reporting pain management programs	C
hospice programs	E
palliative care programs	E
% > age 65 with >7 admissions in last six month of life	B
% nursing home residents in persistent pain	C
State pain policies	B
% certified in palliative care primary care physicians	A
full-time equivalent RNs	B

(Last Acts, Nov. 2002)

Milestones

Grants

1985 **Robert Wood Johnson Foundation:** \$50,000 to hire an Executive Director.

1996 **Maine Women's Fund:** \$4,500 to hold focus groups with older women and to publish "*Listen to Me: Elder Ladies Seeking Input and Empowerment Regarding End of Life Issues.*"

1999 **Robert Wood Johnson Foundation:** \$450,000 for a three-year Community State Partnership Grant, "*Care at the End of Life: A Public/Private Partnership.*"

2002 **The Maine Bureau of Health:** \$55,000 for two projects: to gather hospice baseline data; and, to perform a retrospective quality-of-life chart audit in Maine Veterans Homes.

2003 **Hospice Education Institute:** \$12,500 to support initial development of the Center.

2003 **Maine Health Access Foundation:** \$45,000 planning grant to develop a business plan for the Maine Center for End-of-Life Care.

2004 **The Maine Bureau of Health:** \$30,000 for phase two of the quality-of-life retrospective chart audit. This project is a partnership with the **Maine Health Care Association.**

2004 **Senior Spectrum:** \$2,500 to develop an integrated training program for patients, family members and home-health aides dealing with ALS and other neuro-degenerative diseases.

2004 **Administration on Aging:** \$245,000 for the continued development of the **Maine Center for End-of-Life Care.**

1984 Maine Hospice Council evolves from the merger of two statewide organizations. The new entity is incorporated with 501(c)(3) nonprofit status.

1989 State government passes legislation appropriating general fund allocation for MHC's operations.

1990 MHC publishes *Hospice Care in Maine: A Direction for the Future*, a white-paper highlighting hospice needs in Maine.

1992 MHC hires its current Executive Director, Kandyce Powell, and a new mission is developed reflecting a more comprehensive work plan.

1993 Maine Cancer Pain Initiative is created with support, in part, from the Bingham Consortium for Health Research.

1994 Hospice Licensure, a two-year project of the MHC, becomes law.

1998 MHC commissioned market survey reveals that 50% of the people in Maine know nothing about Hospice and relatively little about end-of-life resources.

1999 Maine Consortium for Palliative Care and Hospice (MCPCH) is convened by MHC and other healthcare and academic partners to promote a more socially responsive environment around end-of-life care.

2001 A Physician-Assisted Suicide Referendum provides an opportunity to increase awareness of end-of-life care issues in Maine. The MHC focuses efforts on educating policy makers and healthcare consumers on existing service barriers to quality care.

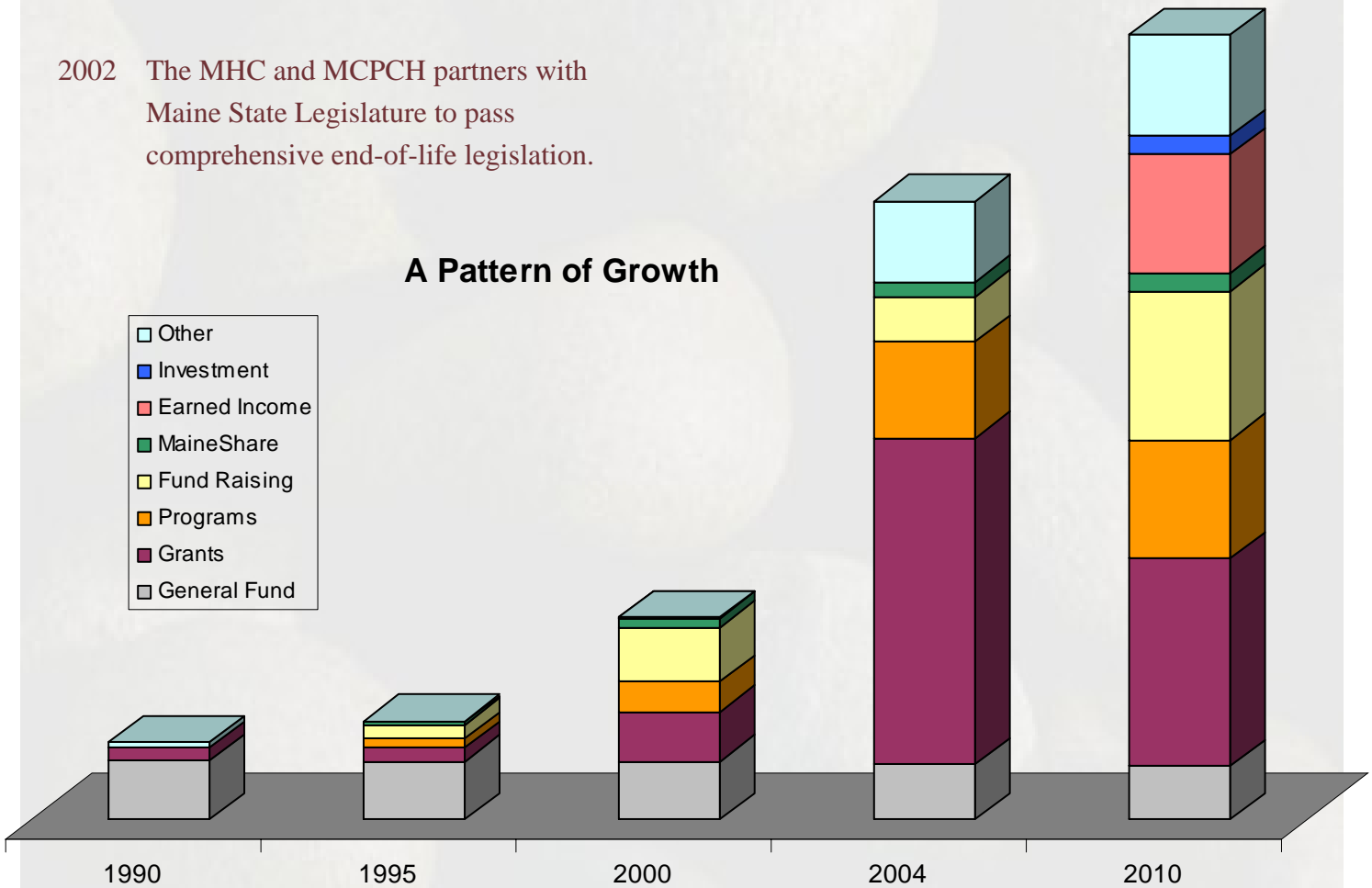
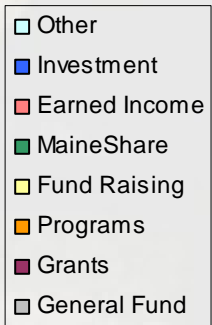
2001 The Maine Bureau of Health formally offers the Council the opportunity to develop the Maine Center for End-of-Life Care (Center). No funding attached.

2002 The MHC and MCPCH partners with Maine State Legislature to pass comprehensive end-of-life legislation.

The Maine Center for End-of-Life Care is a key element of our efforts to improve end-of-life care in Maine and our members look forward to developing the Center as the focus of research, policy development, and education on end-of-life care in Maine.

Maroulla S. Gleaton, MD
 Immediate Past-President
 Maine Medical Association

A Pattern of Growth



1990 Revenue = \$65,000
 General Fund primary revenue source.

1995 Revenue = \$83,000
 28% increase since 1990. Revenue sources are more diverse.

2000 Revenue = \$170,484
 105% increase from 1995. Revenue sources

2004 Revenue = \$521,389
 106% increase from 2000. General Fund appropriation now less than 10%. Grants increase to 50%

2010 Revenue = \$661,000
 Sustained 4% growth. Revenue sources reflect thoughtful consideration to balance and sustainability.

Snapshot 2004

The Maine Hospice Council has been, and remains, the only state-wide nonprofit agency in Maine dedicated solely to improving the quality of end-of-life care. The development of the Center is a natural evolution of the Council's work.

The MHC provides:

- **Advocacy . . .**
. . . for individuals, families, and healthcare providers.
- **Consultation . . .**
. . . to patients, families, healthcare professionals, workplaces, and academic institutions.
- **Technical Support . . .**
. . . regarding program development, fundraising, grant writing and other infrastructure concerns.
- **Education . . .**
. . . for consumers, healthcare professionals, volunteers, and other caregivers.
- **Representation . . .**
. . . at local, state, and national levels.
- **Resources . . .**
. . . developed by the Council as well as other local and national leaders.
- **Collaboration . . .**
. . . and partnership development with local, state, and national organizations.
- **Research . . .**
. . . and data collection to benchmark progress.
- **Placement . . .**
. . . for undergraduate and graduate student interns.
- **Press Releases . . .**
. . . opinion pieces and professional journal submissions.
- **Public Speaking . . .**
. . . to increase awareness.

We are pleased to extend our commitment to work with you to create and sustain the Center, and are available for anything you need.

Kip DeSerres, MSPH
Vice President for Cancer Control, American Cancer Society

Programs and Partnerships Highlights

Consumer Protection

The MHC, together with Maine's Office of the Attorney General, continue to address the following questions: Will my pain be managed? Will my wishes be honored and respected? Will I receive competent care?

Department of Corrections

MHC and Department of Corrections continue to work collaboratively to provide education and training regarding end-of-life issues within the Maine State Prison system.

Hospice/Veteran Partnership

A coalition of interested individuals from the Department of Veterans Affairs, Maine Veterans Homes, Maine Hospice Council and community hospice programs working together to ensure that quality end-of-life care is available for Maine's veterans and their families.

Maine ALS

A partnership to increase awareness and develop educational programs for patients, families, and healthcare providers dealing with neurodegenerative diseases.

Maine Pain Initiative

The MPI, formerly known as the Maine Cancer Pain Initiative, is a committee of the Maine Hospice Council. A multi-disciplinary group of healthcare professionals, consumers, and other interested persons committed to making pain relief a reality for all people in Maine.

Maine Health Care Association and Maine Veteran's Homes

Two partnerships focusing on quality-of-life issues in Maine's long-term-care facilities.

The work of the Center is crucial for the State of Maine, mainly because the Center has identified and targeted many underserved and vulnerable people in Maine.

Magdalena Linhardt, Ph.D.
College of Natural and Social Sciences, University of Maine in Augusta

The Path Ahead

The Maine Hospice Council and the Maine Center for End-of-Life Care are linked by mission, purpose, structure, and staff. Looking to the future of the Center requires looking into the future of the MHC. The Maine Hospice Council has the infrastructure and leadership necessary to develop the Center's program goals. *"The Maine Center for End-of-Life Care will provide a statewide support system for caregivers and for families and patients who are dealing with a very painful and difficult period in their lives,"* say Senators Olympia Snowe and Susan Collins.

Program Goals

Drawing on 20 years of Maine Hospice Council experience and leadership, the work plan will focus on four major areas: community engagement, research and data collection, education and advocacy.

Community Engagement

- Partner with civic organizations, faith communities, and other community organizations to develop programs and projects that address consumer needs.

Research and Data Collection

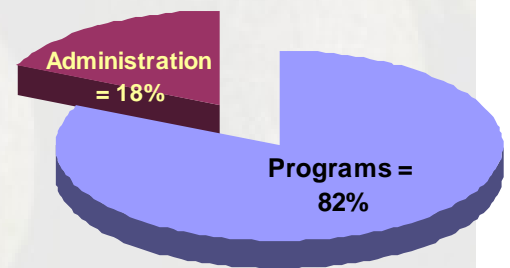
- Develop survey tools; gather baseline data; benchmark progress.
- Catalog and make accessible existing resources.

Education

- Develop appropriate curricula to address the educational needs of healthcare professionals and consumers.
- Develop an interdisciplinary mentoring program.

Advocacy

- Survey legislators regarding end-of-life issues.
- Provide information to policy makers and advocate for appropriate policy changes.



For the past 15 years, the MHC has expended 82% of total revenue for programs while holding administrative costs to 18%.

The goals outlined for the Center are instrumental in the expansion and improvement of hospice and palliative care in Maine.

Dora A. Mills, MD, MPH
Director, Bureau of Health, State Health Officer

Financial Goals

The Center will require substantial funding to accomplish its mission. By operating as a committee of the Maine Hospice Council, the Center draws on the MHC's fundraising successes. Historically, these funding sources range from public and private grants, earned income, special events (annual appeal, membership, bike rides, etc.) and MaineShare.

Increased Capacity Projections:

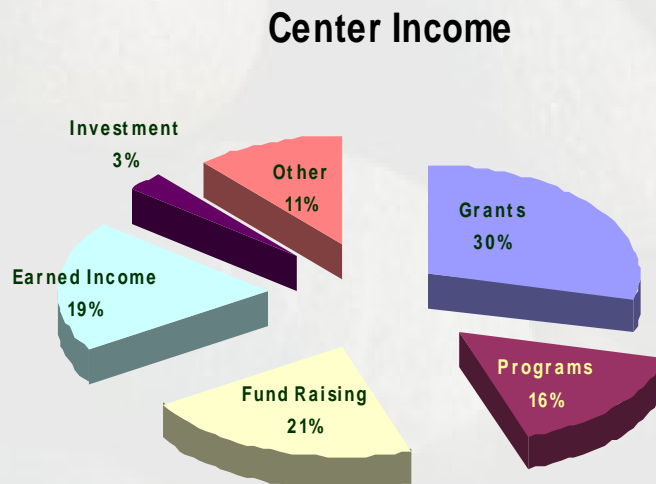
- **Staff:** Medical/Research Director, Education Director and Development/Marketing Director. Anticipated additional annual revenue required: \$226,000.
- **Physical:** New space for resources, offices and storage. Anticipated additional annual revenue required: \$28,500.
- **Resources:** Professional journals, videos, print materials and electronic materials for the Resource Center for loan to consumers and healthcare professionals. Anticipated additional annual revenue required: \$7,500.
- **Marketing/Public Relations:** PSAs, educational materials, advertising. Anticipated additional annual revenue required: \$15,000

In addition to these goals, the work plan will explore the feasibility of developing a charitable Foundation to support philanthropic activities around end-of-life care.

Revenue

The Center's needs will require identifying and cultivating new sources of revenue as well as sustaining existing sources. Anticipated sources of revenue are:

- **Earned Income**
- **Fundraising**
- **Grants**
- **Investment**
- **Other**
- **Programs**



The Center is building on the excellent foundation that the Maine Hospice Council, the Maine Consortium for Palliative Care and numerous collaborators have built in recent years.

Richard Erb, President/CEO
Maine Health Care Association

Investment Policy Statement

The Maine Hospice Council's Portfolio type is directed as an endowment and managed by A.G.Edwards & Sons, Inc. The Portfolio will be managed in a moderate manner with consideration to the changing economic, business and investment market. Portfolio make-up will be consistent with the mission of the MHC and will be balanced, with the primary objective being income with growth. Due to the MHC's status as a nonprofit entity, the Portfolio is non-taxable.

Individual initiatives that the Council will continue to undertake with the proceeds from the endowment will include, but not be limited to:

- Advocacy
- Consultation
- Educational workshops and seminars
- Program and partnership development
- Assistance with analysis of state and federal legislation specific to end-of-life care
- Representation at the national level through board and committee involvement, as well as consulting work.
- Contributions for various publications

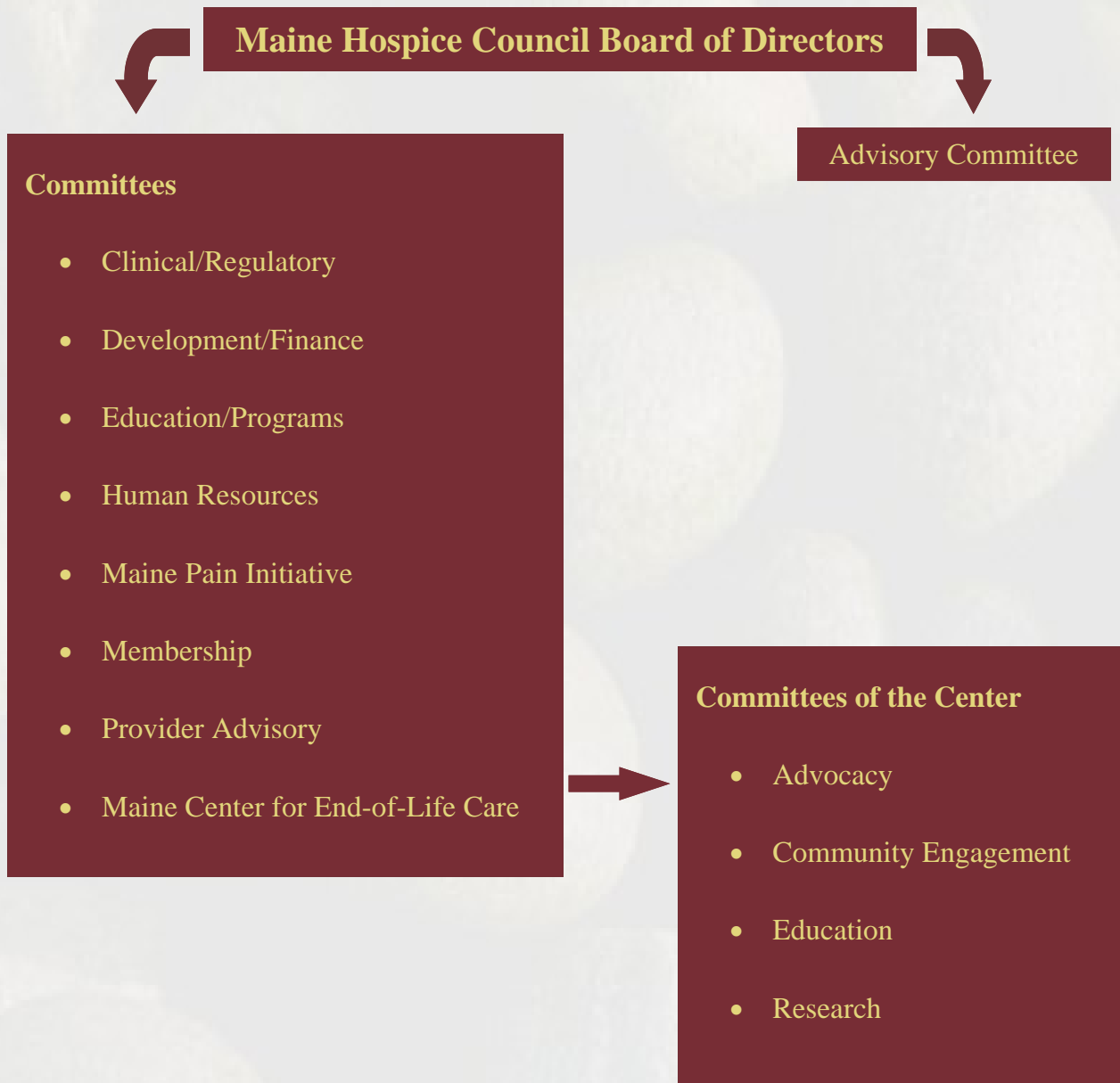
The Portfolio Manager will maintain the fund in accordance with the fiduciary obligation of the 1974 ERISA. Regarding tax issues, it will be the responsibility of the MHC to contact its own tax professional independent of either the investment manager or A.G.Edwards & Sons, Inc.

The Portfolio's performance will be measured on an annual basis against commonly accepted market indices. The fund will be reviewed annually by the MHC Finance Committee; however, a review may be requested at any time on advice of the Portfolio Manager, or by request of the MHC Finance Committee or the MHC Board of Directors.

The Hospice Education Institute pledges its financial and administrative support to your program for the Maine Center for End-of-Life Care. We warmly endorse this excellent addition to the Hospice Community and the people of Maine.

Michal Galazka, Executive Director
Hospice Education Institute

Organizational Structure



As a leader in end-of-life care, the Council provides the role modeling and mentoring needed and welcomed by graduate students.

Amy Line, MSW
Boston College School of Social Work

Partners/Stakeholders

The following organizations are committed to the continued development of the Maine Center for End-of-Life Care. Their commitments to date have been substantial, and they have all agreed to continue their support in the manner best suited to their specific organization.

- American Cancer Society
- Androscoggin Home Care & Hospice
- Department of Corrections
- Department of Health and Human Services
- HealthReach Network
- Home Care Alliance of Maine
- Hospice Education Institute
- The Jason Program
- Laurel Coleman, MD, Geriatrician/Palliative Care
- Maine Alzheimer's Project
- Maine Council of Churches
- Maine Health Care Association
- Maine Hospital Association
- Maine Medical Association
- Maine Osteopathic Association
- Maine Veterans' Homes
- Muskie School of Public Service, Institute for Health Policy
- National Association of Social Workers, Maine Chapter
- Susan Ostertag, MD, Ellsworth Family Practice
- Senior Spectrum
- Togus VA Medical Center
- Two Roads Maine
- University of Maine — Augusta, College of Natural and Social Sciences
- University of New England, Division on Aging and Mature Care
- University of Southern Maine, College of Nursing and Health Professions
- Volunteers of America

There are many organizations willing to serve individuals who are in need of end of life care, but only the Maine Hospice Council stepped up to the plate to work with one of the most disenfranchised group of individuals: offenders.

June Koegel, President/CEO
Volunteers of America

I look forward to working with you and other partners to further develop the Center's capacity for research, policy development and education.

Paul Saucier, Director
Chronic Illness, Disability and Aging Program, Institute for Health Policy
University of Southern Maine, Muskie School of Public Service

Maine Hospice Council Publication Highlights

- 1988 *Guide to Hospice of Maine* providing information for the public about the availability of hospice care in Maine. Periodically revised.
- 1990 *Hospice Care in Maine: A Direction for the Future* . Provides a road map for hospice in Maine.
- 1996 *Listen to Me: Elder Ladies Seeking Input and Empowerment Regarding End of Life Issues.*
- 1996 *An Interdisciplinary Approach to Pain Management*, an interactive television course, created as a demonstration project with the University of Maine System and the Education Network of Maine.
- 1998 *Hospice*. A full-color brochure developed after the MHC Market Research to promote hospice care in Maine.
- 1998 Public Service Announcements developed and aired on all major broadcast media channels.
- 1999 *MaineLink*. The newsletter of the Maine Hospice Council. Published periodically.
- 1999-2002 *Access to End of Life Care in Maine: An Annual Report*. Prepared for the Committee on Health and Human Services
- 2001 *Inpatient Hospice Facilities In Maine: A White Paper*. Written to identify barriers, clarify processes, and recommend needed legislative changes in order to aid in the development of in-patient hospice or palliative care programs in Maine.
- 2002 *A State-Wide Resource Guide of End of Life Care Support Services*. A directory of medical and non-medical resources throughout Maine.
- 2002 *Comparison of Medicaid Hospice Benefit and Medicare Hospice Benefit*
- 2002 *Care at the End of Life: A Public/Private Partnership*. A report on the work completed through the Community/State Partnership program funded by the Robert Wood Johnson Foundation.
- 2003 *Interfaith Dialogues for End of Life Ministry*. A manual for building successful, faith-based ministries to address death, dying and life at the end of life.
- 2003 *Maine's Legislative Approach to Expanding Hospice Access*. Written by Spann Publications Consulting, LLC and printed in *State Initiatives in End-of-Life Care* (Issue 20, Nov. 2003).
- 2004 *Maine Hospice Council: Promoting Excellence in End of Life Care 2004 Annual Report*.



Maine Hospice Council, Inc.

Promoting Excellence in End of Life Care

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