TO: House Committee on Human Services  
Senate Committee on Health and Welfare

FROM: Cindy Bruzzese, Vermont Ethics Network  
Members of the Palliative Care and Pain Management Task Force

SUBJECT: Annual Report on Activities, Progress and Recommendations related to Act 25; Section 18; Palliative Care and Pain Management Task Force

DATE: January 15, 2010

Introduction
In Section 18 of Act 25, the general assembly requested (contingent upon funding) that the Vermont Ethics Network “convene a task force to coordinate palliative care and pain management initiatives in Vermont, help people to gain access to services, and propose solutions for addressing gaps in services and educating consumers about their rights under the patients’ bill of rights for palliative care and pain management”. The details of this report summarize the recommendations, activities and progress of the task force on work related to these specified goals and objectives.

Recommendations
1. Legislative support and participation in a statewide Palliative Care and Pain Management Summit on March 22, 2010 at Gifford Medical Center
2. Legislative support for a statewide public report based on the outcomes of the Palliative Care Summit containing recommendations for improvements in palliative care and pain management for all Vermonters
3. Funding from the state to implement recommendations as described in the final published report in order to continue this important work.

Background
Efforts to improve palliative care and pain management have been a focus of national attention for the past several years as well as a focus of the Vermont General Assembly.

In 2002, the Attorney General’s issued a report highlighting how Vermont rated with respect to several criteria:

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certification of medical professionals in palliative care</td>
<td>A</td>
</tr>
<tr>
<td>Hospitals reporting management/palliative care programs</td>
<td>C</td>
</tr>
<tr>
<td>Nursing home residents in persistent pain</td>
<td>C</td>
</tr>
<tr>
<td>State pain policies</td>
<td>D</td>
</tr>
<tr>
<td>Hospitals with hospice programs</td>
<td>D</td>
</tr>
<tr>
<td>State Advance Directive laws</td>
<td>F</td>
</tr>
</tbody>
</table>
The publication of this report mobilized stakeholders, policy makers and providers to make improvements in Vermont. This included:

- **Act 162 (2004)**
  - Combined “Living Will” and “Durable Power of Attorney for Health Care” forms
  - Eliminated mandatory Advance Directive form
  - Gave precedence to agent’s authority or most recent statement over “Living Will”

- **Act 25 (2009)**
  - Defined Palliative Care: “Interdisciplinary care given to improve the quality of life of patients and their families facing the problems associated with a serious medical condition. Palliative care through the continuum of illness involves addressing physical, cognitive, emotional, psychological, and spiritual needs and facilitating patient autonomy, access to information, and choice.”
  - Patients’ Bill of Rights: All patients have the right to state-of-the-art pain management, and explanation of all options at the end of life.
  - Required a detailed report on possibility of concurrent palliative and curative treatment for children (due October 1, 2009)
  - Required more detailed reporting on deaths: every two years, how many received hospice care within last 30 days of life, etc.
  - **Sec. 18. PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE**
    - The general assembly requests that VEN convene a task force to coordinate palliative care and pain management initiatives in Vermont; help people to gain access to services; and propose solutions for addressing gaps in services and educating consumers about their rights under the patients’ bill of rights for palliative care and pain management.
  - **Sec. 19. BOARDS OF MEDICAL PRACTICE AND NURSING REPORT**
    - Report from Boards of Medical Practice and Nursing regarding their recommendations for improving the knowledge and practice of health care professionals in Vermont with respect to palliative care and pain management.

Additionally, in 2008 the Center to Advance Palliative Care in collaboration with the National Palliative Care Research Center, published a National Report Card in an effort to understand the prevalence of, and hence access to, hospital palliative care programs in the United States. The criteria measured for this study was the percent of a state’s hospitals, of greater than 50 beds, with an identifiable palliative care contact person or program. The study did not assess the structure of the program or how services were accessed by patients and consumers.

The following tables summarize the findings related to the prevalence of hospitals with a palliative care contact person or program, as well as the distribution across the United States for the grade that the state received based on the criteria measured.
Three states received a grade of “A”:
1. Vermont (100%)
   a. 6 of 6 hospitals with > 50 beds
   b. 7 of 9 hospitals with <50 beds
2. Montana (88%)
3. New Hampshire (85%)

In comparison, a 2002 national report, found that no states received a grade of A or B, and only two (Vermont and the District of Columbia) received a grade of C.

Regarding Qualified Palliative Medicine Physicians and Hospice Utilization:

Qualified Palliative Medicine Physicians:
- **As of 2007**: 2,651 physicians board-certified in palliative medicine (1 physician per 31,000 persons living with serious or life-threatening illness)
  - Compared to 16,800 cardiologists (1 per 71 heart attack victims) and 10,000 oncologists (1 per 145 newly diagnosed cancer cases)
  - 8 in Vermont
- **As of 2008**: 1,271 physicians passed American Board of Medical Specialties exam in hospice and palliative medicine
  - 47 pediatricians

Hospice Utilization:
- Approximately 1/3 of eligible patients avail themselves of hospice services
- Median length of stay: 15 days
Average ~25 days

- 25% enroll in last week of life

**Background Pertaining to Pain Management:**

*Power over Pain Initiative (2004)*

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Patients reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain at least monthly</td>
<td>64%</td>
</tr>
<tr>
<td>Moderate or worse pain</td>
<td>57%</td>
</tr>
<tr>
<td>Lose sleep</td>
<td>50%</td>
</tr>
<tr>
<td>Experienced &gt;3 years</td>
<td>48%</td>
</tr>
<tr>
<td>Receiving treatment</td>
<td>33%</td>
</tr>
<tr>
<td>Referred to pain specialist</td>
<td>21%</td>
</tr>
<tr>
<td>Of those who received treatment, who improved</td>
<td>90%</td>
</tr>
</tbody>
</table>

**Task Force Activities**

- **Distribute and Collate Survey on Current Structure, Gaps and Recommendations:** In order to achieve the goals set forth in Section 18 of Act 25 regarding palliative care and pain management, a preliminary survey was distributed to providers in the hospital, home health and community setting to collect information related to the current structure of how palliative care and pain management services are being delivered and accessed in all regions of the state. Currently, this information is not well understood, nor does it exist in a place where it can be readily accessed and utilized.

- **Convene Statewide Conference on March 22, 2010:** The Vermont Ethics Network, in conjunction with the Task Force, will convene a statewide Palliative Care and Pain Management Summit consisting of an interdisciplinary group of stakeholders, professionals, policy makers and consumers. Utilizing information obtained from the returned surveys as the background and foundation for discussion, the group of attendees will work to collectively determine strategies and recommendations for improvement. Vermont Ethics Network will publish a public report outlining those recommendations and will make that document available through the Vermont Ethics Network website. This report will serve as the plan to guide future efforts of the Task Force in achieving the goals set forth in Section 18 of Act 25.

**Public Education and Awareness Progress**

While a very limited amount of funding ($1000) for the Task Force has been obtained to date, progress toward specified goals related to public awareness and education have been initiated. This includes:
Access to the Patient’s Bill of Rights for Palliative Care and Pain Management via the newly created on-line resource: Vermont Palliative and End-of-Life Care Resource Connections (http://vtpcrc.vtdesignworks.com/index)

Appearance on Across the Fence. “Hospice and Palliative Care in Vermont” taped on November 25, 2009. Aired on December 7, 2009 and is scheduled to re-air on January 19, 2010. We have also received an invitation to appear quarterly on Across the Fence in an effort to keep Vermonters aware of issues.

Additionally, there has been a collaborative approach between the Vermont Ethics Network, the Task Force, the Board of Medical Practice, the Board of Nursing, the Vermont Medical Society, the Vermont Association of Hospitals and Health Systems, and others to work together to respond to the requests of the general assembly and to strategize methods for addressing long term needs related to improvements in community education, provider education and training, and access to palliative care and pain management services. We are confident that the March 22nd Summit will prove a necessary first step toward further progress.

Working Members of the Task Force

- Cindy Bruzzese, Vermont Ethics Network
- Diana Peirce, Central Vermont Home Health and Hospice; Hospice and Palliative Care Council of Vermont
- Christina Melvin, UVM College of Nursing
- Patricia Launer, Vermont Program for Quality in Health Care
- Jackie Majoros, State Long Term Care Ombudsman
- Trinka Kerr, State Health Care Ombudsman
- Stephen Kiernan, Community Member
- Beth Stern, Community of Vermont Elders
- Sarah Lauderville, Vermont Center for Independent Living
- Ann Mallett, Lamoille Home Health and Hospice