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To: Montana House Human Services Committee

EXHIBIT 1
DATE 3-7-05
HB 742

Re: HB 742

Date: March 7, 2005

Madame Chair, members of the committee. My name is Lilly Tuholske, and I am the executive director of the Life's End Institute: Missoula Demonstration Project.

The Life's End Institute is part of a national movement to improve end-of-life care. We are one of the oldest and most well known of community end-of-life organizations nationwide. I am here in support of this bill, which proposes a relatively simple Internet-based registry to store the documents containing declarations people can make under Montana law regarding their end-of-life health care.

At the Institute, our mission is to improve the quality of life of people who are dying, and of their families. And we do that through research and community projects.

We have studied advance care planning – the process by which people can make their end-of-life wishes known in a living will and in a power of attorney for health care.

There are two important findings from our work:

- First, the conversations that people have about their end of life wishes, conversations they are likely to have as a part of advance care planning, are directly associated with making things easier at a time of life when almost nothing is easy.
- Secondly, too often advance care planning documents cannot be found when they are needed, creating confusion and uncertainty during crisis times.

Let me tell you a story from my own family to illustrate this latter point. Last April, my mother in law, who lived in St Louis, happened to be in Florida when she suffered a heart attack. My husband, who was her designated representative in her power of attorney for health care, contacted the hospital immediately, because

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we knew, given her age – 83 – that she was gravely ill. Did the hospital have a copy of her advance directives? No, they did not. And so my husband faxed the documents to the hospital, asking that they be included in her chart. By the time he arrived in Florida soon thereafter, she had been transferred to another hospital. Did they have her advance directives? No, they did not. My husband then contacted me and I was able to fax the documents once again.

After several weeks, after my mother in law had developed pneumonia and was not getting better, we decided to transfer her via air ambulance to a hospital in St. Louis, so she could be nearer to her friends and things that were familiar to her. I arrived there the next day. Seeing that my mother in law was very weak and in bad shape, I took the one of her doctors aside, and I asked whether he had her advance directive documents. He did not. And so I called my husband from the hospital hallway, and he sent the documents, now for the third time, via fax.

All of this occurred at a great emotional burden to us, and also at a burden to my mother in law, who was consulted each time the documents were transferred. This is not how we wanted to spend our time. These conversations made her angry, and they made her cry, when she wanted to talk about her grandchildren and when she might see them again.

HB 742 is about using a proven Internet system so that advance directives can be accessed at any time, from anywhere. It's about alleviating suffering and confusion at a time when moments are precious.

On May 28, my mother in law died with my husband and I at her side. In the end, although she had suffered terribly, her final moments were peaceful, and the health care wishes she had expressed in her living will were honored and respected – but not without a great deal of effort, when all we really wanted to do was be with her.

We live in a mobile society, when families are often separated by many miles. And yet we live in a computer age. HB 742 is a simple bill that uses the Internet to help alleviate suffering among Montana families.

I urge your support of this bill.

Thank you.

