

# ***VERMONT2008***

## *Advance Directive Registry*

Report to the Legislature on **Act 55**  
January 15, 2008



**DEPARTMENT OF HEALTH**  
**Agency of Human Services**

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## **Executive Summary**

Act 55, An Act Relating to Advance Directives for Health Care, was enacted by the General Assembly and signed into law by the Governor in June 2005. In accordance with Act 55, the Department of Health was required to adopt rules to effectuate the intent of the law, implement an Advance Directive Registry, provide information about advance directives and the Registry to public agencies and to the general public, and report to the Legislature and the public on the utilization of the Registry and integration with the Anatomical Gift Registry.

This report describes the implementation of the Advance Directive Registry, education and outreach efforts to promote advance directives and encourage people to use the Registry, and progress toward the integration with the Anatomical Gift Registry.

The final Advance Directive rule and forms became effective on January 8, 2007. The Department implemented the Registry through a contract with a web application service provider, and announced its availability to the public in February 2007. The Department awarded a grant to the Vermont Ethics Network (VEN) to help promote advance directives and the Registry through public education and information sessions at senior centers, public libraries, churches, and assisted and community living facilities. As of December 17, 2007, 1,325 advance directives have been registered.

To overcome the limitations of the Advance Directive Registry to capture organ donations indicated only on motor vehicle operators' licenses, the Department is working with the Department of Motor Vehicles on a plan to have Vermont participate in an existing organ donor registry operated by StatLine that serves most of the New England States.

## ***Introduction***

Act 55, An Act Relating to Advance Directives for Health Care was enacted by the General Assembly and signed into law by the Governor in June 2005. Act 55 required that the Vermont Department of Health adopt rules to effectuate the intent of the law, develop and maintain an advance directive registry, provide a sticker that can be placed on a driver's license or identification card indicating that the holder has an advance directive in the registry, and provide on the department's public website information on advance directives and the registry to appropriate state offices.

This report describes the implementation of the Advance Directive Registry, education and outreach efforts to promote advance directives and encourage people to use the Registry, and progress toward the integration with the Anatomical Gift Registry.

### ***1 Implementation of the Registry***

18 V.S.A. §9719 requires the Department of Health to develop and maintain an Advance Directive Registry and to promulgate rules and specific forms, including at least one optional form of an advance directive with explanation of choices and responsibilities, a form for Clinician Orders for Life Sustaining Treatment (COLST), the use of identification and consistent statewide emergency medical standards for DNR Orders and advance directives for patients and principals in all settings. The final rule and forms became effective on January 8, 2007.

To implement the registry, the Department of Health contracted with US Living Will Registry (USLWR). This vendor has successfully operated a web-based advance directive registry in several states for over ten years. USLWR proposed to customize their existing registry to meet Vermont needs, and provide web-hosting services.

On February 2, 2007, the Commissioner of Health sent a letter to all Vermont hospital CEOs announcing the availability of the Advance Directive Registry. This

correspondence included a copy of the rule explaining obligations under Act 55, and a provider access agreement and application for setting up a registry account. The announcement served to commence a 120 day implementation period during which providers were required to establish protocols, train staff, and make other preparations to ensure that the registry is checked before providing services to people who lacked the capacity to make health care decisions. The Commissioner of Health also sent announcement letters to all physicians licensed in Vermont, and submitted articles about the registry to provider association newsletters and publications to ensure that all classes of “providers” affected by the legislation were aware of the registry and their new obligations under the law.

During the 120-day implementation period, the Department of Health collaborated with the Vermont Ethics Network on education and technical support presentations to providers and professional groups including hospitals, Vermont Funeral Directors, Vermont Cemetery Association, Probate Court judges, and state human services departments such as Mental Health and Aging and Disabilities. The presentations covered provider obligations, operation of the registry, forms, the registration process, and the registry website. In addition, the Department teamed with the Vermont Medical Society (VMS) and Vermont Association of Hospitals and Health Systems (VAHHS) to conduct two conference calls for medical, ethics, and social services staff at Vermont hospitals. Based on the questions raised during those conference calls, Frequently Asked Questions (FAQs) pages were posted on the VMS and VAHHS websites.

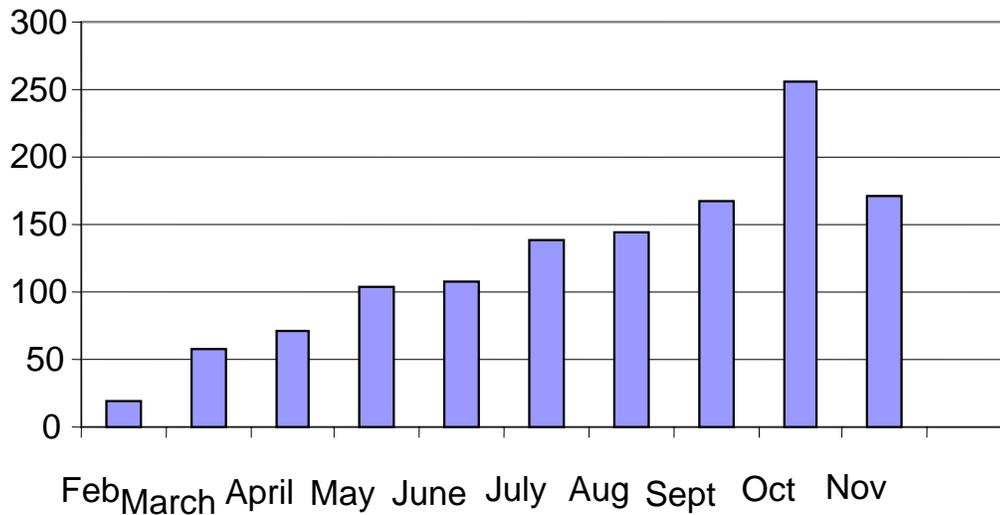
The Department of Health website ([www.healthvermont.info/vadr](http://www.healthvermont.info/vadr)) is another means of informing both providers and the general public about advance directives and the registry. The website is organized into registrant and provider sections. The registrant section explains how to register and offers a number of different advance directive forms. The provider section covers responsibilities, the statute and rule, procedures and protocols, forms, registration procedures, change notification, and technical support. Both sections have links to the registry.

## ***2 Education and Outreach***

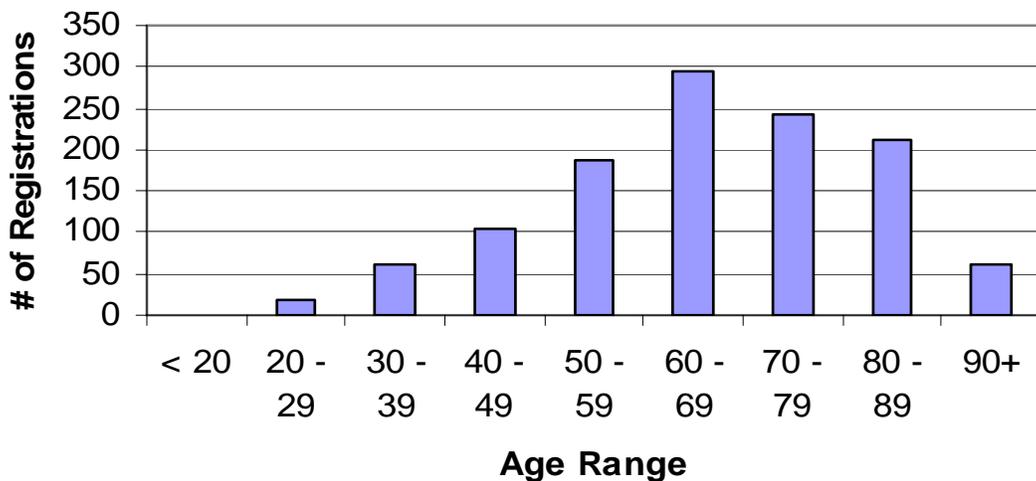
The Department of Health awarded a \$12,000 grant to the Vermont Ethics Network (VEN) to help promote advance directives and the Registry. Throughout 2007, VEN conducted public education and information sessions at senior centers, public libraries, churches, and assisted and community living facilities. VEN did presentations, workshops, and set up display booths at health fairs, community clinics, and conferences including: Southeastern Vermont Council on Aging Caregivers Conference; Central Vermont Medical Center staff conference; Vermont State Nurses Association conference; Aging in Place Fair; Winooski Senior Center; National Association of Social Workers conference; and the Vermont Statehouse. In 2007, VEN's presentations have reached approximately 1,000 Vermonters. In addition to presentations and interactive discussion, VEN developed a new booklet called *Registering Your Advance Directive* featuring Vermonters. All of VEN's information materials and forms are available on its website ([www.vtethicsnetwork.org](http://www.vtethicsnetwork.org)).

The effectiveness of these outreach efforts is evidenced by increasing number of advance directive registrations. Since February 5, 2007, when the Commissioner of Health announced the availability of the registry to the general public, 1,325 people have registered their advance directives (as of December 17, 2007). The registry averaged 50 enrollments per month in the first quarter of operation, 116 per month in the second quarter, and 144 per month in the third quarter following Governor Douglas's Proclamation of Advance Directive Week in September. Of those who have registered to date, 55% are female and 45% are male. They range in age from 20 to 99 years, with two-thirds 60 years and older. The following charts display the growth in registrations by month, and the age distribution of registrants.

### 2007 Advance Directive Registrations by Month # of Resignations



### 2007 Vermont Advance Directive Registrations by Age



### ***3 Integration with the Anatomical Gift Registry***

Through an advance directive, an individual may declare their wish to make an anatomical gift upon their death. The individual can register their advance directive with the Vermont Advance Directive Registry, and use the stickers provided through registration to signify on their license or insurance card that they are an organ donor. Then organ procurement organizations, as authorized providers, can determine that the individual is an organ donor by accessing the registry. In this way, the Advance Directive Registry also serves as the Anatomical Gift Registry, as long as organ donors make their anatomical gifts using an advance directive.

However, there are other ways to make an anatomical gift. The most common way is to check and sign the statement on the reverse side of a Vermont motor vehicle operator's license. It is estimated that nationally about a third of drivers consent to organ donation on their license, but relatively few of those people have included that information in a registered advance directive.

In order to register anatomical gifts that are only indicated on drivers' licenses, the Department of Health is working with the Department of Motor Vehicles on a plan to have Vermont participate in an existing organ donor registry that serves most of the New England states. The Department of Motor Vehicles plans to modify its licensing process to collect organ donation information and store it in their new information system. Periodically, they will electronically send organ donation information to this separate registry which is operated by StatLine. StatLine receives, organizes, and stores this information, and makes it available to organ procurement organizations. Organ procurement organizations will continue to have access to the Vermont Advance Directive Registry for anatomical gifts that are made through advance directives.