



Susan Bysiewicz
SECRETARY OF THE STATE
CONNECTICUT

Testimony of Secretary of the State Susan Bysiewicz
Public Health Committee Hearing
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S.B. No. 1144- 'AN ACT ESTABLISHING A CENTRAL INDEX
FOR ADVANCE HEALTH CARE DIRECTIVES'

Good morning Chairwoman Handley, Chairwoman Sayers, and members of the Public Health Committee. For the record, my name is Susan Bysiewicz, and I am the Secretary of the State of Connecticut. Thank you for the opportunity to appear before you today to offer testimony in support of S.B. 1144 *An Act Establishing a Central Index for Advance Health Care Directives*. I want to thank the Committee for raising S.B. 1144.

This bill would allow for the creation of an online Advance Health Care Directives Registry in my office that would offer Connecticut citizens a virtual filing cabinet in which to file their Advance Health Care Directives documents.

Suppose you are caring for an elderly parent who is suddenly in need of emergency medical attention. Your parent has already filled out a Living Will, but now you can't find it or contact your parent's lawyer. You have no way of knowing what your parent's wishes are, and the document that spells them out is nowhere to be found. What do you do now? If a doctor treating your mother or father needs to know if they should perform extraordinary life-saving measures, or if a feeding or breathing tube should be used, how are you supposed to give them the correct answer? Your parent may have carefully outlined those wishes but may not have shared all that information with you. Now, imagine the same scenario, only this time you remember that your parent had registered his/her Living Will with the Connecticut Advance Health Care Directives Registry and you have a photocopy of the registry card in your wallet. You quickly access the online Advance Health Care Directives Registry in your computer where you find the document with detailed health care directives.

Scenarios like this one have occurred before, and have often required children or next of kin to make nearly impossible or very difficult decisions at the most emotionally stressful times. There are times when Advance Health Care Directives, such as Living Wills or Appointment of a Health Care Agent, simply

cannot be located, and the person who filled them out is unable to speak for himself. The consequences of such a situation can be tragic – a person's express wishes may not be carried out.

There are three reasons why I think an online Advance Health Care Directives Registry makes sense in Connecticut:

1. Individuals get added peace of mind in knowing that critical health care information is stored safely and securely and is always accessible when most needed.
2. Family members should not carry the burden of having to guess what their loved ones would want in a given crisis situation.
3. Health care professionals need certainty in carrying out patients' wishes when it comes to life-saving situations in which the patient is unconscious.

Anyone could have Advance Health Care Directives such as a Living Will or the appointment of an agent for health care decisions registered in the index. It would be easy to do so:

1. They would obtain a copy of the Advance Health Care Directives registration form from our website or by mail.
2. They would mail copies of their directives with the signed registration form to my office.
3. The registration form and documents would be scanned.
4. These documents would be fed into the online registry as electronic replicates with assigned file numbers.
5. They would receive a wallet-sized card (similar to an organ donor card) in the mail with the website address, password, and file numbers.

These documents would be accessible online, 24 hours a day, 7 days a week, to family members in an emergency if they have the password and file number.

There are precedents for the creation of an online registry of Advance Health Care Directives in Connecticut. At least seven other states have created or are in the process of creating Advance Health Care Directives registries. Both North Carolina and Arizona have successfully established online registries, North Carolina in 2002 and Arizona in 2004. Montana and California established their registries in 2004 and 2005. As of February 1 of this year, Vermont has also

activated an online Advance Health Care Directives registry. Other states may soon draft similar legislation.

I have contacted the Secretaries of the State in North Carolina and Arizona, and they have informed me that their online Advance Health Care Directives registries have worked very well and been useful to their residents, with 8,000 registrations in North Carolina since 2002 and 7,000 in Arizona since 2005.

Several groups and organizations in Connecticut have collaborated with us on and support and endorse this legislation for the creation of the online Advance Health Care Directives Registry. These include Connecticut Hospice, American Association of Retired Persons, Connecticut Commission on Aging, Advocacy for Patients with Chronic Illness, Inc., and the Connecticut Medical Society. The Attorney General of Connecticut also joins me in supporting the creation of this registry in our state. Lastly, for the committee's information, we are also working with the Connecticut Hospital Association to improve and streamline the proposed legislation.

Distinguished members of the Public Health Committee, S.B. 1144 makes sense from both a personal and social policy perspective. It would send a clear message that it is important for everyone in Connecticut to prepare and securely file Advance Health Care Directives as a part of their health care planning. In closing, I strongly urge the Committee to approve the creation of this Advance Health Care Index in my office and to move forward with S.B. 1144.

Thank you for your consideration of this important piece of legislation and at this point I'll be glad to answer any questions you may have.