



compassion & choices  
of new york

**Summer 2006 Issue**

PMB 2010, 244 5th Avenue  
New York, NY 10001  
212.561.9175

www.compassionandchoicesofny.org  
email: ny@compassionandchoices.org



Non-Profit Org.  
U.S. Postage  
PAID  
Portland OR  
Permit No 2762

CHANGE SERVICE REQUESTED

## oregon releases 8th annual report on aid-in-dying law

Oregon's Department of Human Services recently released its eighth annual independent report on the use of Oregon's aid-in-dying law.

According to the report, 38 Oregonians ended their lives under the Oregon aid-in-dying law compared to 37 who did so in the previous year.

"Once again, our report shows little change in the demographics and characteristics among those who are using this law," said Mel Kohn, M.D., state epidemiologist. "And again, these deaths reflect a very small portion of the average 31,000 annual deaths in Oregon."

Since the first case of aid-in-dying there have been 246 Oregonians who died under terms of the law. As in prior years, participants were more likely to have cancer (84%) and be younger than others with terminal illnesses (median age of 70 years). They also had more formal education (37% had at least a baccalaureate degree).

### Other findings:

- Thirty-nine physicians wrote a total of 64 prescriptions for the medication in 2005.
- Thirty-six patients died in their own homes and two died in assisted living facilities. Thirty-five patients were enrolled in hospice care at their death.
- All patients had some form of health insurance; 58% had some form of private health insurance and 42% had Medicare or Medicaid coverage.
- As in previous years, the three most often mentioned end-of-life concerns were a decreasing ability to participate in activities that made life enjoyable (89%), loss of dignity (89%), and loss of autonomy (79%).

The full report and information about Oregon's aid-in-dying law may be found going to the state's website at: <http://www.oregon.gov/DHS/ph/pas/docs/year8.pdf>

## board news

Board President **Florent Morellet** was honored for his activism on AIDS by AmFar (American Foundation for AIDS Research) at the Rainbow room on June 7. He is also the Grand Marshall at the Gay Pride Parade on June 25 along with City Council President Christine Quinn, a supporter of Compassion. These are wonderful tributes.



Board member **Debbi Gibbs** has been elected to the national Compassion & Choices Board of Directors. Congratulations Debbi!



## new website launched

We have a new website! Just at the time we were thinking about developing a new website, longtime supporter, Susan Lewenz, President of Axxiem Corp. offered to build and design a new website for us as part of their AxxiCARE work with non profit organizations. She and her colleague, Nate Binzen, did a wonderful job, for which we are very grateful. One board member, expressing the consensus of the entire board, commented, "I think it's an excellent web site — interesting, imaginative, professional." Please check out the website at [www.compassionandchoicesofny.org](http://www.compassionandchoicesofny.org). It has a good deal more information than the old website. We welcome your feedback. For any of you interested in getting help with a website, contact Axxiem Corp, 17 Kent Ave., Hastings On Hudson, NY, 10706, Tel: 914-478-7600, fax: 914-478-6384, email: [info@axxiem.com](mailto:info@axxiem.com), website: [www.axxiem.com](http://www.axxiem.com)



Printed on Recycled Paper with 30% post-consumer content using Soy-based ink.

# message from the executive director

The Supreme Court's 6 to 3 decision upholding the right of physicians to prescribe lethal medicines for their dying patients in Oregon was a major victory for those of us who support choice at the end of life.

The Court rejected the Attorney General's claim that he alone can determine what constitutes medical practice for the entire country by criminalizing certain practices he doesn't like. The Court agreed with arguments made by Compassion & Choices that Ashcroft's analysis of the Controlled Substances Act was owed little deference. It rejected the claim that Congress "delegate[d] a single Executive Officer the power to effect a radical shift of authority from the States to the Federal Government to define general standards of medical practice in every locality." As the Court noted, "the Attorney General claims extraordinary authority" in the Ashcroft Directive, and if Ashcroft's view of the Controlled Substances Act were upheld, the Attorney General's "power to criminalize . . . would be unrestrained." The Court rejected the Attorney General's strained analysis of the CSA in terms that amounted to scolding. Justice Kennedy wrote that, "The idea that Congress gave the Attorney General such broad and unusual authority through an implicit delegation in the CSA's registration provision is not sustainable. Congress . . . does not, one might say, hide elephants in mouseholes."



David Leven, Executive Director, Compassion & Choices of New York.

***"The idea that Congress gave the Attorney General such broad and unusual authority through an implicit delegation in the CSA's registration provision is not sustainable. Congress . . . does not, one might say, hide elephants in mouseholes."***

— Justice Kennedy, U.S. Supreme Court

It is hoped that the Supreme Court decision will be a catalyst to help bills pass that are now pending in the California and Vermont state legislatures, similar to Oregon's Death with Dignity Act.



Alberto Gonzales, United States Attorney General.

## pain legislation moving forward

Compassion & Choices of New York has been playing the major leadership role in seeking legislation in New York State to address the public health crisis of the under-treatment of pain. The status of two bills that we have been working on is briefly described below:

### **Safe Harbor Bill**

A.7643 (Gottfried), the "safe harbor" bill, passed the Assembly unanimously on April 3. Sponsored in the Senate by Health Committee chair Kemp Hannon (S.5016), the bill would protect from prosecution or professional discipline physicians who are providing effective pain care, providing

they do so in accordance with the reasonable standard of care of the profession, including an accepted guideline. Those who fail to provide effective pain care could be subject to prosecution or professional discipline. We have met with leaders from the Department of Health and the Governor's office to discuss their concerns with this bill, and they are developing suggested amendments.

### **Palliative Care Bill**

We are also working on a "Palliative Care Education and Training Act." This bill has

*Continued on page 3*

connections



compassion & choices  
of new york

Summer 2006 Issue  
PMB 2010, 244 5th Avenue  
New York, NY 10001  
212.561.9175

www.compassionandchoicesofny.org  
email: ny@compassionandchoices.org

# nyc attorneys hear about physician aid in dying

## *Association of the Bar of the City of New York Committee Hears About Physician Aid in Dying and Disabilities*

In March, David Leven and Professor Asch addressed the Standing Committee on Legal Issues Affecting People with Disabilities. The disability community is divided on the issue of aid in dying. David made the case as to why people with disabilities should not oppose aid in dying laws, which apply only to the terminally ill, and there were many reasons to support them. David noted that people with disabilities have been discriminated against historically as well as today, including by the medical profession, and expressed an understanding of why those who are disabled might at first be skeptical and have concerns about aid in dying laws. However, David argued that eight years of expe-

rience under the *Oregon Death With Dignity Act* have provided sufficient evidence that there need not be fears and that the right to choice and autonomy, a core principle of the *Americans with Disabilities Act*, should be available to all citizens including those in the disability community

However, none of the people who have taken lethal medicines in Oregon had a previous disability. And as Dr. Paul Spiers, a former President of End of Life Choices, a current Compassion & Choices board member and a wheel chair user for the past 12 years, has correctly stated, "people with disabilities are far more vulnerable where laws governing aid in dying do not exist." He says, "If, as our opponents

maintain, the life of a person with a disability is less valued by society, then such patients are far better protected in Oregon where the process is transparent and has safeguards, requiring a written request, independent consultation, counseling if depression is present, and a waiting period." If he were ever terminally ill, Dr. Spiers has commented, he would want to be able to exercise choice. As he has stated, "It might not be your choice, or that of ten other people with disabilities or who use wheelchairs, but just as I would never presume to make a choice for you, please do not presume to make a choice for me. You do not have to somehow protect me from myself, from others, or from society just because I am a wheelchair-user. I prefer to protect myself."

# advocates warn against post-Schiavo legislation

One year after Terri Schiavo's husband, Michael, won a legal battle for the right to have her wishes respected and a feeding tube removed, two national patients' rights organizations, MergerWatch Project and Compassion & Choices warned about the danger of legislation introduced in 23 states that would make honoring patients' wishes to forgo life-sustaining treatment more difficult. A list of 49 proposed laws introduced in 2005 and 2006 state legislative sessions was released by the two organizations dedicated to protecting patients' rights to self-determination.

Compassion & Choices President Barbara Coombs Lee warned, "These proposed laws would authorize an army of vigilantes to challenge a family's decision to remove a feeding tube. Religious institutions, politicians and right to life groups could intrude in a family's most intimate and difficult decision, tying them up in court for years." The two organizations called for public policies ensuring that patients' wishes to forgo life-sustaining

## *Advocates for patients' rights warn against restrictive post-Schiavo legislation; call for policies to ensure that patients' wishes to forgo life-sustaining treatment will be honored.*

treatment will be honored and for better enforcement of existing laws requiring disclosure of any institutional restrictions on honoring advance directives.

### **Of the 2005 and 2006 legislative proposals identified as of mid-February 2006:**

- 40 would restrict forgoing artificially administered nutrition and hydration.
- 20 bills in 13 states are based on the National Right to Life Committee model legislation entitled "Starvation and Dehydration of Persons with Disabilities Prevention Act."
- 14 bills have additional restrictions beyond the National Right to Life Model bill.

The National Right to Life model bill requires that artificially administered nutrition and hydration (ANH) be provided to patients without decision-making capacity except in very

narrow circumstances. For example, doctors could not withhold or withdraw ANH for patients who did not explicitly mention ANH even if the patients: (1) had completed living wills explicitly stating that they did not want any life-sustaining treatment if they were in a persistent vegetative state, (2) had appointed a health care agent with broad authority to make all treatment decisions, including forgoing all life-sustaining treatment, and (3) had repeatedly told their doctors that they never would want their lives artificially prolonged if they are in a persistent vegetative state.



*Barbara Coombs Lee,  
President, Compassion  
& Choices.*

## educating the legal profession

### Law Students

During the past several months David Leven debated and spoke at a number of law schools in New York following the favorable ruling on aid in dying in *Gonzales v. Oregon*. At Cardozo, Columbia and CUNY Law Schools, David engaged in dialogue with Adrienne Asch, Professor of Bioethics, Yeshiva University, Wurzweiler School of Social Work on whether the terminally ill should have a right to aid in dying. While not disagreeing with most of the points David made as to why laws should be passed nationwide giving dying people the choice to have lethal medicines prescribed for them, Professor Asch argued that the existing Oregon law did not have sufficient safeguards. This despite the fact that of the hundreds of people who have been prescribed lethal medicines and the 246 who have taken them, no evidence exists of coercion or any other abuses. The Oregon experience has been similar to ours in New York in that those who express an interest in hastening their deaths often have to persuade loved ones that this a reasonable choice for them and they need to be supported in that choice given their circumstances.

At Hofstra Law School and New York Law School (which had the largest attendance of almost 70 students) David spoke by himself. At each law school the audiences were very receptive.

### Nassau County Bar Association Presentation

David addressed some 60 attorneys at a Continuing Legal Education program on the topic of "What if Terri Schiavo Lived in New York." After reviewing relevant cases in New York and the Florida lower court and appeals court decisions, David said that it is not clear that a court in New York would have found, as the Florida courts did, that there was clear and convincing evidence of Ms. Schiavo's wishes. If the New York courts had ruled differently, Ms. Schiavo, if she lived in New York, might still be alive. The Schiavo case, among many others illustrates the need for people to complete a health care proxy.

## preaching to faith, ethical and inquiring communities

About 20 members of the Bedford Presbyterian Church heard David Leven speak on two consecutive Wednesdays, first on end of life issues including pain management, health care proxies and the Schiavo case and then on issues relating to hastening death.

At The Ethical Society of Northern Westchester, with a number of hospice volunteers and staff present, David spoke on "Choice in Dying: Current Issues and What is at Stake."

Congregants at the United Memorial Methodist Church in White Plains heard David speak on end of life decision making where he raised a number of practical and ethical hypotheticals for people to discuss.

At the Center for Inquiry Long Island, David spoke on "End of Life Decisions: Who is in Charge?" The program was taped for local cable access TV and we received positive feedback from one viewer with no previous connection to Compassion

If you belong to a faith congregation and would like to try to help arrange for a speaker, please contact David Leven at 914 907-6156.



*David Leven, Executive Director, Compassion & Choices of New York, speaking at Hofstra Law School.*

## Legislation...Continued from page 1

been introduced in the Assembly, A11162 and Senate, S7458, by the chairs of the Health Committees in both houses. It would do the following: establish a statewide advisory body on palliative care (which includes pain management); create undergraduate and graduate palliative care training programs, with funding of around 4.5 million dollars; establish state Department of Health-designated palliative care "centers of excellence," and authorize the Department of Health to certify one or more palliative care resource centers to assist physicians in the treatment of patients in pain.

We have received tremendous support and assistance from leading pain care and palliative care physicians.



*Diane Meier, MD, Director, Center to Advance Palliative Care and Director, Hertzberg Palliative Care Institute, Mount Sinai School of Medicine.*

However, the bill might never have been introduced in the Senate were it not for Dr. Diane Meier, Director of Center to Advance Palliative Care of the Hertzberg Palliative Care Institute at Mount Sinai School of Medicine. She helped to interest Senator Kemp Hannon, chair of the Senate Health Committee, by writing a compelling letter to him about a patient of hers whose pain previously had been significantly undertreated and then by bringing her patient to a meeting with Senator Hannon who listened as she told her tragic story. The patient, Denyse Dolny (whose name we have permission to use) gave a moving account of how her pain was ineffectively treated by leading oncologists, and only when she was treated by Dr. Meier, was her pain finally controlled, as it could and should have been earlier.