



COMPASSION IN DYING®  
of New York

Autumn 2004 Issue  
PMB 2010  
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## Pain Bill Legislative Hearing Goes Well

**O**n November 5, the first of two legislative hearings on the Assembly pain legislation, A. 10407 was held. The second hearing is scheduled for January 26 in Albany. The legislation, introduced at the urging of Compassion in Dying, would require pain management courses in medical schools; require continuing medical education courses for physicians, pharmacists and nurses in pain management; protect physicians from disciplinary or state criminal sanction for treating pain effectively if the physician is practicing in accordance with a nationally recognized health care standard; and make clear that failure to treat pain properly could result in professional discipline.

All who testified spoke of the need to improve pain care in New York State and supported the goals of the legislation. A large majority of those testifying supported the bill itself. Concerns were raised by some about the need for mandated medical school curricula since almost all medical schools in New York State have begun to incorporate into existing or new courses teaching about pain and palliative care. Whether or not mandatory continuing education courses are desirable was another issue raised.

Among those testifying or submitting testimony at the hearing were

pain patients, pain and palliative care specialists, and end-of-life and other organizations representing those who unnecessarily suffer pain. Cynthia Hildt, a school teacher who was forced to retire because of her “dreadful, ongoing pain”, spoke movingly about the problems that she encountered over the years. “I was never given anything near to meeting my needs,” she stated. Her doctors “seemed, to a person, more concerned that I would become a drug addict than anything else - certainly that was, they thought, too important a risk to take.” It was years before she found a physician who treated her pain well and who treated her with compassion.

Others who testified included: Joseph J. Fins, MD, FACP, Chief, Division Medical Ethics and Professor, New York Weill-Cornell Medical Center; Kathy McMahon, President and CEO, Hospice and Palliative Care Association of NY; Michael Brescia, MD, Executive Medical Director of Calvary Hospital, Bronx, NY; Xinru Qian, MD, American Board of PM&R, TCMA; David Keepnews, PhD, JD, RN, Director, Office of Policy Development, New York Academy of Medicine; Steven A. King MD, Co-Director, Pain Center, Hospital for Joint Diseases, Clinical Professor, NYU School of Medicine; Siobhan Reynolds, family member of a

## Ashcroft v. Oregon: The Attorney General Loses Again but Appeals to the Supreme Court

**I**n the insert with the spring newsletter we reported that the United States Court of Appeals had just issued a 2-1 opinion, which soundly rejected Attorney General John Ashcroft’s claim that he had authority under the Controlled Substances Act to revoke the prescribing licenses of physicians who prescribed lethal medicine for their terminally ill dying patient in Oregon. Ashcroft was rebuffed again when he asked the entire court to hear the case. Only one of twenty five judges was interested, the dissenting judge. Ashcroft has now appealed to the U.S. Supreme Court.

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Chronic Pain Patient, President of PRN (Pain Relief Network); Sylvia A. Law, Elizabeth K. Dollard Professor of Law, Medicine, and Psychiatry, NYU Law School; Ling Zheng, Licensed Acupuncturist; Philip Nobile, family member of a patient; Ellen Coleman, Associate Executive Director, Cancer Care. Testimony was submitted by Diane Meier, MD, Director of Center to Advance Palliative Care of the Hertzberg Palliative Care Institute at Mount Sinai School of Medicine.

# Message From the Executive Director

Six years of data from Oregon on the functioning of the Oregon Death with Dignity Act demonstrate that, by all accounts, this experiment with physician assisted dying (PAD) has been remarkably successful. None of the problems predicted by those opposed to the law have materialized. The law has been used sparingly. Only 171 people have actually died using lethal medicine prescribed by their physicians. Almost all have had health insurance and between 80% and 90% are enrolled in hospice where they get very good end of life care.

In Oregon, physician assisted dying is legal, strictly regulated and above ground. Although one in six dying Oregonians think about assisted dying, just one in fifty discuss it with their physicians and only 1 in 1,000 die by ingesting prescribed lethal medicines. This compares with 1 in 250 people who die with a physician's assistance in six other states studied where PAD is illegal and unregulated. It is also estimated that some 68 violent deaths have been prevented, thus avoiding terrible agony for family members. About half of those who contemplated a violent suicide later used prescribed lethal medicines.

A large majority of those people who hasten their deaths in Oregon, according to



*David Leven, Executive Director, Compassion in Dying of New York.*

a report by the Oregon Department of Health Services, do so because of concerns regarding autonomy and control at the end of their lives. Specifically, the most commonly mentioned were loss of autonomy, decreased ability to participate in activities that make life enjoyable and loss of dignity.

Although the Supreme Court rejected claims in 1997 that people had the right to physician assisted dying either as a matter of equal protection or as a due process liberty right, it left the decision on this issue to the laboratory of the states. Oregon's law has proven to a model that should be replicated across the nation. Much needs to be done to lay the ground work for that to happen in many states, including New York. However, even without the law there is so much that we can still do for patients, within existing law, to help ensure a peaceful death with dignity.

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## Unification of Compassion in Dying and End-of-Life Choices Approved

At the end of October the boards of Compassion in Dying and End-of-Life Choices unanimously agreed to unify the two organizations under the name Compassion and Choices. According to new Compassion and Choices Board Chairman, Robert V. Brody, MD, "The two arms of Compassion and Choices, Compassion in Dying and End-of-Life Choices will be governed with one board of directors and will function with common purpose, mission and strategies. They will share internal services, including administration, information technology, human resources and communications. The End-of-Life Choices arm is led by

Marsha Temple who oversees membership, legislative and political advocacy, and local groups. The Compassion in Dying arm is led by Barbara Coombs Lee who oversees the offices of legal advocacy, client services, public education and development."

In concluding a letter sent to local affiliate and chapter leadership, Dr. Brody said, "We are clearly a social movement whose time has come. Compassion and Choices is positioned to realize the goals of our movement. These goals are that every person has access to excellent care and the choice of a peaceful and humane death at the end of life. Together we can reach these goals."

Connections



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## On the Airwaves & in Print

Channel 9 in Rochester hosted David Leven who spoke about the pain legislation and the need for upstate legislators to sponsor the pain bill.

In September, Patient Support Coordinator Judy Schwarz and David Leven were on a one hour "Health Styles" radio program on WBAI, a New York radio station, talking about feeding tubes and health care proxies.

David was on WVOX, a Westchester radio station, in June, speaking about health care proxies, feeding tubes and pain management.

Also in June David was a guest on a WLIE (Long Island) radio program where he discussed the problem of undertreatment of pain and proposed remedial legislation that addresses the causes.

*The New York Times* published a letter to the editor in July by David supporting physician assisted dying, in response to a column by Nicholas Kristof that praised the Oregon Law.

In November David was on a half hour local access Cablevision program in Westchester County speaking about physician assisted dying, pain management, health care proxies and hospice.

In October, *The Journal News*, a Westchester, Rockland newspaper, published a letter to the editor by David on the "Fundamental right to control one's care", regarding decisions on feeding tubes.

## See "The Sea Inside"

This Spanish film is an absorbing and poignant tour de force about a quadriplegic's desire to die with dignity. It tackles the subject of assisted dying with intelligence and grace. It won the best picture award at the Venice Film Festival and is likely to be a contender for the best foreign language film in the United States. It opens in New York City on December 17.

## Networking with Other Justice Department Adversaries

End-of-Life Choices sponsored and Compassion in Dying co-sponsored a program at New York Society for Ethical Culture bringing together speakers from diverse organizations who are seeking to thwart Attorney General John Ashcroft's attempts to intrude upon personal health care decisions. The program, entitled "Dr Ashcroft Will See You Now: Why is the Department of Justice re-defining the Practice of Medicine", featured panelists from The Center for Reproductive Rights, Drug Policy Alliance and Compassion in Dying of New York. Priscilla Smith spoke about

how the Justice Department is trying to enforce the "Partial Birth Abortion Act". Bill Piper described the investigations and prosecutions of medical marijuana collectives and individual prescribers, and the case now before the Supreme Court on the right to grow and possess medical marijuana for one's own consumption. David Leven discussed the *Ashcroft v. Oregon* litigation. The program was hosted by Robert Raben, End-of-Life Choices National Advocate and Scott Schell, The Brennan Center for Justice, New York University School of Law.

## Panel on Key Health Legislation at The New School

Assemblyman Richard Gottfried, Chairman of the Assembly Health Committee, was the featured speaker at a forum held at The New School in October. As the prime sponsor of the Family Health Care Decisions Act and the pain bill, he spoke about their importance, the likelihood of passage and the roadblocks still to be overcome. Tia Powell, MD, Executive Director of the New York State Task Force on Life and the Law, which had drafted the Family Health Care Decisions Act, talked about the history of the bill and the ongoing efforts to ensure passage of the bill. Lauren Shaiova, MD, who specializes in work-



Assemblyman Richard Gottfried, Chairman of the Health Committee.

ing with patients with cancer, HIV and sickle cell pain, as an attending physician at Beth Israel Medical Center

Department of Pain Medicine and Palliative Care, described her work with pain patients in supporting and demonstrating the need to enact the pain legislation. David Leven moderated the panel discussion which was followed by a reception with wine and hors d'oeuvres graciously provided by Restaurant Florent.

## Family Health Care Decisions Act Now Has Twelve Senate Sponsors: Passage Possible Next Year

The Family Health Care Decisions Act, proposed legislation that would enable family members to make health care decisions for incapacitated loved ones when there is no health care proxy, now has twelve Senate sponsors. They include senators: Seward, LaValle, Bonacic, Hoffmann, Larkin, Little, Maziarz, McGee, Morahan, Saland, Spano and Volker. In the spring of 2003, the bill had but one sponsor when it was first introduced in the Senate, largely as the result of our efforts.

The bill, S. 5393, needs your support. If your state senator is not a spon-

sor, we encourage you to write him/her about the importance of the bill and asking him/her to co-sponsor it. Also please write to the Chair of the Senate Health Committee, Senator Kemp Hannon, 708 LOB, Albany NY 12247, asking him to co-sponsor the bill. Send copies of your letters to Senate Majority Leader Joseph L. Bruno, 909 LOB Albany, NY 12247. Sample letters can be found on the Family Decisions Coalition website, [www.familydecisions.org](http://www.familydecisions.org). Please contact us if you need your senator's address.

## On the Road for Compassion

In October, David Leven was the opening plenary speaker at the Education for Physicians on End of Life Care (EPEC) Conference in Buffalo. The conference attendees learned of the perspective of an advocate for dying patients on gaps in communication, the need for physicians to engage in advance care planning, the futility of inserting feeding tubes in the frail elderly and those with advanced Alzheimer's, issues of pain management and the pain bills Compassion is working on, the Family Health Care Decisions Act, physician assisted dying and stopping eating and drinking to hasten death.

David gave a talk to some 50 health care professionals at Monroe Community Hospital in Rochester focusing on the problems of undertreatment of pain and what health care providers need to know about misconceptions regarding pain in the elderly, the issues concerning feeding tubes in the elderly, and the peaceful way of dying by stopping eating and drinking for those who, at the end of their lives, are ready to let go.



*Byron Roy, Chairperson of Concern for the Dying, and David Leven at Monroe Community Hospital.*

Also in Rochester, David was a plenary speaker at the fall meeting of the Elder Law Section of the New York State Bar Association where he talked about the pain bill and its vital importance for improving pain care; he stressed the urgent need to pass the Family Health Care Decisions Act, since only about 20% of New Yorkers have health care proxies and, as a result, health care decisions for the great majority of patients lacking capacity ultimately get made by health care professionals rather than by loved ones.

## Florida Supreme Court Rejects Bush Appeal on Schiavo Case

On October 21 the Florida Supreme Court rejected Governor Jeb Bush's request to reconsider its unanimous September ruling which would allow for Mrs. Schiavo's feeding tube to be withdrawn in accordance with her previously stated wishes. In its September decision the Court held that a law, passed by the Florida legislature, giving the governor authority to order the reinsertion of the feeding tube in Mrs. Schiavo, was unconstitutional.

Compassion in Dying applauds the court rulings that would allow Mrs. Schiavo's wishes to be honored. However, this tragic case is not over yet. Attorneys for Mrs. Schiavo's parents are seeking a new hearing. They claim that Mrs. Schiavo, who they assert was a devout Catholic, would have wanted to be kept alive had she known of the Pope's recent pronouncement which condemns the removal of feeding tubes as "euthanasia".

## Outreach

### Hospice Connections

Judy Schwarz has made connections, as the result of working with different patients, at Jacob Perlow hospice, VNS hospice and Hospice of New York. Since we refer all of our terminally ill patients to hospices if they are not already enrolled, it is important that we maintain effective working relationships with these hospices. We also want these programs to refer patients to Compassion, when appropriate. David Leven has recently communicated with staff at Hospice and Palliative Care of Westchester.

### Patients Increasing Each Year

The number of patients to whom we provide intensive counseling on end of life issues continues to rapidly grow. Last year, we served 12 new patients. This year, on the strength of 10 months' experience, we are projecting almost 30. Eleven of the patients we have served this year have died, four by hastening and three by terminal sedation. Many of these patients and their family members are counseled over a period of weeks or months.

### Seniors

We continued meeting with senior citizens at a number of locations this summer and fall. David Leven spoke to seniors in New Rochelle, Eastchester and White Plains. Because of the large number of elderly people who do not have health care proxies, we now distribute proxy forms at our meetings.

*David Leven visits the Eastchester Senior Citizens' Center.*

