

President's Letter

Dear Members and Friends,

Changes are being made to the Beacon and to the Hemlock Society of Florida. The Beacon will now be issued twice a year—in April-May and Sept-October. The reason for the change is due to lack of “workers.” It is an overwhelming task for two people to produce four issues per year. Perhaps in the future, when the Board of Directors increases in membership, there will be sufficient staff to produce more issues. I hope this meets with your approval and understanding.

The second change will be in staff. In the fourteen years of the state organization’s operation there has never been any paid staff. I have informed the Board of Directors that if help is not

forthcoming I will no longer be able to continue. Being the president of the Hemlock Society and Foundation of Florida is more than a full-time position (all volunteer). The office and most archives of the organizations are maintained in my home. In addition, Hemlock of Florida has an ‘800’ phone number, also in my home. I take calls from the entire United States, since the Florida organization is the only “Hemlock” listing in the ‘800’ directory. Most calls involve answering questions about the organization and sending callers a packet containing our brochure, a suggested reading list and the Advance Directive, with a cover letter. I also send a brochure from Final Exit Network since Hemlock does not offer similar services.

To expedite this workload, the Board of the Hemlock

Society of Florida has approved the hiring of a clerical assistant. This action took place at the April 19th meeting in Orlando. The search for this person will begin immediately.

Following this meeting, a

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Hemlock Society of Florida, Inc.

Beacon Newsletter

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public gathering was held in the afternoon featuring Robert Rivas as speaker. Mr. Rivas is the Legal Advisor to the Hemlock Society and Foundation of Florida.

In early March, the Hemlock Society of Florida and Final Exit Network of Florida co-sponsored ten meetings throughout the state. The purpose of these meetings was to acquaint residents with the purpose and function of each organization. Most of the meetings had a speaker from Hemlock and the Network to give background on how and why the organizations were formed. Following these presentations, time was allotted to answer questions from the audience. There was good attendance at the meetings and all seemed to think it was a worthwhile venture. Perhaps, in the future, we can have additional meetings in other towns in the state. It appears that there will be several areas forming informal get-togethers for discussion of various end-of-life topics.

Donna

FILE OF LIFE

The File of Life is now available at a cost of two dollars (\$2.00) each. This cost includes postage for mailing. You can obtain the File of Life by sending a check (payable to the Hemlock Society of Florida) to P. O. Box 121093, West Melbourne, FL 32912-1093. You may order as many packets as you need. It makes a nice gift to a friend or relative.

THANK YOU

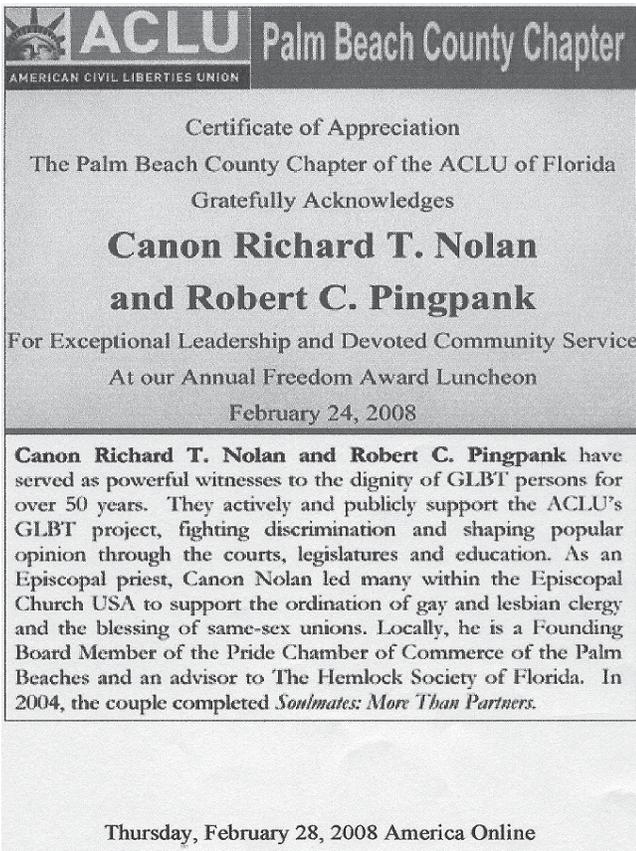
A big thank you to all who have renewed their membership in the Hemlock Society of Florida and also sent donations to the Hemlock Foundation. Beginning with this issue of

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the Beacon, there is an expiration date included in the address area. If there is no date (e.g., Jan 2009) by your name, it means you are not a member of the Florida organization. Remember that if you pay dues to Compassion and Choices (C&C) this does not qualify you for joint membership in the Hemlock Society of Florida (HSOF). We are independent of any other right-to-die organization. For some of you it may be a financial burden to be a member of C&C, HSOF and, perhaps Final Exit Network, which is why the dues to HSOF are low. Again, the Board of Directors thanks you for your continued support.

Another thank you is given to those of you who have offered to organize local discussion groups in your area. Many of you have requested meetings and we are now offering discussion groups and meeting details listed in each Beacon. If you are interested in hosting a group in your area, please call Donna Klamm at 1-800-849-9349.

We are also grateful to Final Exit Network members Jim Chastain and Mike McGoldrick for organizing the meetings that were held in March which have led to the formation of new groups. These meetings will be supported by the Hemlock Society of Florida and Final Exit Network of Florida.



CANON NOLAN HONORED

Our congratulations to Canon Richard T. Nolan who was recently honored by the Palm Beach County Chapter of the American Civil Liberties Union for his exceptional leadership. Canon Nolan has been an Advisor to the Hemlock Society of Florida since its inception in 1994. He is an outstanding individual who, for many years, has given himself to serving others. We are proud to be associated with him.

Around the World

AUSTRALIA - The province of Victoria has initiated a program called The Respective Patients' Choices which allows patients in the early stages of chronic or terminal illness to make a formal written statement declaring their decisions to refuse life-saving treatment in hospitals. Proponents say this will save families from having to make such decisions for loved ones, but the Australian Medical Society says the program has too many "legally grey" areas. The program manager says it is not about euthanasia but "allowing nature to take its course."

Death With Dignity Victoria said an overwhelming majority of Australians believe in the right of the terminally ill to seek and obtain medical assistance to end their lives with dignity.

CZECH REPUBLIC - Czech legislators say the time is not right for legalization of euthanasia. However, they do think that better care of the dying is needed. It was noted that health care facilities would have to honor documents previously written by patients who wish not to prolong treatment; this is permitted by current law. Many legislators and medical personnel oppose euthanasia for fear there would be abuse.

Tomas Halik, president of the Czech Christian Academy said that "euthanasia might be a horrible weapon in the war between generations." However, he admitted, "it is ethically justifiable to interrupt or not apply a treatment that is obviously ineffective."

(This review is from a Czech News Agency article.)

FRANCE - A recent case in France reveals that more needs to be done to care for chronically and terminally ill patients. The case has reopened the public discussion for laws on euthanasia. The case in question involved Chantal Sebire, a 53-year old former school teacher, who suffered from a rare disease that produced disfiguring facial tumors and would eventually attack her brain and kill her. She had asked politicians to allow her physician to assist her in ending her pain-wracked life without fear of the doctor being prosecuted.

Unfortunately, the legislature and the court ruled against her. Some legislators said she could possibly enter a hospital and receive terminal sedation which she did not want. Sebire said, "I want to go out celebrating, surrounded by my children, friends, and doctors before I'm put to sleep definitively at dawn."

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Following the court decision, Sebire stated, "I know how to obtain what I need, and if I cannot obtain it in France, I will obtain it elsewhere." According to friends, she implied that she would go to Dignitas in Switzerland.

Sebire died the day after the court decision denied her request for euthanasia. Following an autopsy it was determined that she had died of an overdose of barbiturates.

An article in Time magazine reported that, according to doctors familiar with the disease suffered by Sabire, [it can] "routinely be controlled through early detection and surgical removal of the tumors, and [the patient can] go on to lead a normal life." Apparently Sebire refused surgery and palliative care.

LUXEMBOURG – The World Federation of Right to Die Societies recently announced that on February 19, 2008 the Grand Duchy of Luxembourg approved a bill on the decriminalization of euthanasia. World Federation President, Jacqueline Herremans said, "Patients now have the right to medical assistance to make the ultimate moment of their life an act of freedom." President Herremans also congratulated Jean Huss and Lydie Err who have been fighting many years to gain this legal right.

NETHERLANDS – A recent report noted that there is increasing use of drugs for terminal sedation rather than legal euthanasia. Terminal sedation is the use of drugs to induce what is called a continuous deep sedation shortly before dying. The study showed an increase of this method from 5.6 percent to 7.1 percent, while the use of euthanasia decreased from 2.6 percent to 1.7 percent.

Judith Rietjens of Erasmus University Medical Centre in Rotterdam said, "While euthanasia is regulated by law and carries strict conditions, deep sedation is considered part of regular medical practice and typically used in the last few weeks in life."

UNITED STATES – Clinton - Presidential candidate Hillary Clinton was asked about her attitude toward Oregon's physician-aid-in-dying law. In typical politically-correct lingo, she said it was the right of states to make such laws—"whether I agree or not." When asked if she would have voted for the law if she had been a resident of Oregon, her response was "I don't know the answer to that...with appropriate safeguards and informed decision-making, I think it's an appropriate right to have."

Florida - James Mahorner, a retired attorney, of Jacksonville has sued for his

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right to die. Mr. Mahorner is 76 and suffers from mini-strokes which are eroding his brain. He wants the right to have a doctor help him die when the time is right. He is asking a federal judge to issue an order for his doctor to assist in his dying without fear of prosecution. Mahorner says he is pursuing this now, while he is still mentally competent, although he is not yet ready to die. He says he wants his doctor's assistance once he becomes incompetent or unconscious.

The U.S. Supreme Court ruled in 1997 that there is no constitutional right to assisted-death, but basically left the issue to the states. In Florida assisted suicide is a felony punishable by up to 15 years in prison.

Interestingly, Mahorner had not discussed his decision to file the lawsuit with either his doctor or his children. No further word has been released on this case.

For those of you who do not recall, a similar case was heard in Palm Beach County in 1997 when the ACLU and Hemlock Society of Florida presented the case for Dr. Cecil McIver to assist in the deaths of four terminally ill individuals. By the time the case reached the court only one patient was still alive. His name was Charles Hall. The court ruled in favor of allowing Dr. McIver

to assist in the death of Mr. Hall without fear of prosecution. Unfortunately, the ruling was immediately challenged and the Florida Supreme Court ruled against the doctor and Mr. Hall. The attorney for Dr. McIver and Charles Hall, et al, was Robert Rivas who is the Legal Advisor to the Hemlock Society of Florida.

Kevorkian – On January 15, 2008, ACCENT, the University of Florida student-led speakers' bureau, presented a talk by Dr. Jack Kevorkian in the Stephen C. O'Connell Center at the University of Florida in Gainesville. Due to security concerns the program started 30 minutes later than planned. The audience numbered slightly over 4,800, mostly UF students, indicating youth interest in the Death with Dignity cause or, in some cases, just plain curiosity about the doctor. Dr. Kevorkian announced upfront that his parole requirements precluded discussion of hastened death for the terminally ill. Instead he described, at length, his libertarian worldview. Twice Kevorkian was reminded that his time was up but continued talking. Finally, the Dean of the Law school offered several pre-selected questions for Dr. Jack. Following this question-and-answer period, there was a brief intermission to allow a faculty panel to assemble onstage to discuss the doctor's comments. Unfortunately, many attendees

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departed since it was nearly 10:30 p.m. Four members and guests of the Hemlock Society Board left at the intermission, as did many of the students.

Oregon - The 2007 Annual Report of the Oregon Death With Dignity Act was released in early March. The Report notes that 85 lethal prescriptions were issued with 46 patients taking the medications, 26 died of their disease, and 13 were still alive at the end of 2007. Three additional patients died during 2007 who had received the medications earlier (prior to 2007) bringing the total DWDA deaths to 49. The estimate is 15.6 DWDA deaths per 10,000 total deaths. A total of 341 DWDA deaths have occurred since the law was passed in 1997. The most frequent end-of-life concerns patients mentioned were loss of autonomy (100%), decreasing ability to participate in enjoyable activities (86%), and loss of dignity (86%). Participants were more concerned about inadequate pain control (33%) than in previous years (26%). Most patients (90%) died at home and were under hospice care (88%).

The question is raised as to why more states are not adopting a Death With Dignity Act similar to the Oregon law since the records show that it is working very well. There has been no “slippery slope” as so many had predicted. How can the

general public be educated about this and that it is the *patient’s choice* and no one else’s? With the “baby boomers” entering seniordom, the discussion will undoubtedly become more prevalent.

The 2007 Summary of Oregon’s Death With Dignity Act can be read online at www.oregon.gov/DHS/ph/pas .

Washington State - If you are a member of any right-to-die organization, you probably have received solicitation for money to help get the Washington State Death with Dignity initiative on the 2008 ballot. If you have not received a solicitation for money and would like to contribute to this cause, you can send your check payable to **It’s My Decision PAC, P. O. Box 21984, Seattle, WA 98111**. It is certainly an important cause—we need to have more states with an Oregon-type law. Let’s work together to get the laws passed in many more states.

All articles in the Around the World section have been gleaned from the ERGO news list with the exception of the Kevorkian and Oregon articles.

BOOK REVIEW

Unplugged: Reclaiming Our Right to Die in America by William H. Colby

Reviewed by Donna Klamm

Although this book was published in 2006, I think it is a worthy book to read. Author

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William Colby was the lead attorney for the Cruzan family in their effort to remove life support from their daughter Nancy. It was the first right-to-die case heard by the United States Supreme Court. Mr. Colby was just beginning his practice of law when he was appointed to the Cruzan case. His superiors told him it would be a “short” case. Needless to say, it took several years to decide the fate of Nancy Cruzan. Since that time, Mr. Colby has worked with right-to-die issues and is extremely knowledgeable on the topic.

Throughout the book he refers to the three most publicized right-to-die cases in the United States—Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo. He also constantly comments on the importance of communicating with one’s surrogate, family members and doctors about one’s end-of-life care.

One issue that surprised—no, shocked—me was that Mr. Colby does not have a Living Will. He states that he has informed his wife, children (all minors), his sisters and his doctors of the actions he wants and those he does not want. He is convinced that by constantly communicating his wishes, he has made them “second nature” to his surrogate (his wife), alternate surrogates (his sisters), his doctors and his

children. He feels that informing the people who will eventually be responsible for his care is the most important issue, since circumstances change as we age and, perhaps, our wishes for care and treatment (or non-treatment) also will change.

He talks about many end-of-life issues which we all must consider, including medical technology that can keep patients alive with no hope of recovery and what can be done about this. Various surveys in recent years have found that the majority of respondents would prefer to spend their final days at home with family but, unfortunately, most spend their final days in institutions, often connected to life-support systems.

Mr. Colby cites some of the many advances in medical technology in the past fifty years. It is staggering to realize that there is so much medical equipment to keep the human body functioning when there is no hope of recovery. He tells about three doctors who were faced with medical decisions and the use of this modern technology. When is it appropriate to continue to keep an individual alive? When is it appropriate to decide that the treatment for recovery is futile and move on to offer palliative care? These are very difficult questions for any

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physician and a patient's family.

I recall that some fifty years ago, when my mother was dying of cancer, the only treatment offered was an "oxygen tent" and a limited use of morphine. There were no decisions to be made. Today there is, what one doctor calls, the "dark side" of medicine. When do you determine that the treatment is futile? Where is the fine line between life and non-life? The cases of Quinlan, Cruzan and Schiavo emphasized this issue.

Another issue that Mr. Colby addresses, is that "Americans have a constitutional right to make decisions about their own medical treatment." And once you are unable to make these decisions, it is up to your surrogate to follow through with your prior instructions. Colby states, "We need to talk, not only with the person to whom we've given decision-making power, but with everyone we think might be in that room when decisions are made."

Colby devotes a chapter of the book to his own decision-making issues and again stresses the importance of communication with everyone involved in a patient's health care. He states in several chapters of this book that he does not have a living will. He notes that the President's Council "reported that fewer than 25 percent of Americans

have filled out a living will...16 percent of those documents made it into the patients' medical charts." He then concludes that if these figures are correct, only four percent of patients in hospitals have living wills in their medical charts. In addition, Colby comments from another survey, that "65 percent of doctors would not follow a living will if the instructions conflicted with their own views about a patient's prognosis or expected quality of life." Again, the need to communicate is vital.

Colby also covers issues about feeding tubes; the concerns of the disabled community; the Oregon Death with Dignity Act; and hospice, which he calls the hidden jewel. He discusses the Physician Orders for Life-Sustaining Treatment (POLST) which basically is a document of a patient's wishes written by the physician. Apparently it is intended to have more "clout" than an individual's living will.

The book concludes with several pages of notes (referencing Colby's sources), a bibliography/reading list, and resources for the reader.

It is a well-written book that is easy to read—no legalese here. I do hope you have an opportunity to read Unplugged and pass it along to your spouse, surrogate, caregiver, children, and even encourage your physician to read it.

HELPFUL WEBSITES

www.finalexit.org/ergo-store
to purchase ERGO books/DVDs/
downloads

www.finalexit.org

www.assistedsuicide.org

www.finalexitnetwork.org

www.worldrtd.net

COMING EVENTS

JACKSONVILLE – *Hemlock Meetings*

June 21 – Presentation by Final Exit Network

August 16 – Program to be Announced

October 18 – Program to be Announced
Willowbranch Library (*all meetings*)
2875 Park Street

- All meetings will be at 10:30 a.m.
- Information & Directions:

Call Lamar Strother at
904-388-7860

Please call Lamar to confirm meeting date since library has been known to cancel on short notice.

BOCA RATON AREA -

May 12 - 1:30 p.m.

Spanish River Library
501 N.W. Spanish River Blvd.
Boca Raton, FL 33431

Speaker: Arnold Siegel, Elder Law Attorney.

WEST PALM BEACH AREA -

June - Date, Time and Place to be announced

For info call Barbara 561-582-5712 or Mike 561-625-8177

IN MEMORIAM

Carol Abell Hanauer

Patricia C. Hart

John V. Wilson

DONORS

We would like to recognize individuals and organizations that have donated to the Hemlock Society of Florida and the Hemlock Foundation of Florida. Your financial support is critical to the operation of these organizations and is greatly appreciated.

REMINDER: If you want your donation to be deductible from your income tax, your check must be made payable to the Hemlock Foundation of Florida, Inc. Your dues and donations to the Hemlock Society of Florida, Inc. are not tax deductible.

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Hemlock Society of Florida, Inc.

MEMBERSHIP APPLICATION

Membership dues are **\$20 per person per year**

- New Member Name: _____
(Make check payable to Hemlock Society of Florida, Inc.)
- New Member Name: _____
(Make check payable to Hemlock Society of Florida, Inc.)
- Additional Donation Amount _____
(If you would like a tax credit for this donation, make check payable to Hemlock Foundation of Florida, Inc.)
- Beacon Donation Amount _____
(If you would like a tax credit for this donation, make check payable to Hemlock Foundation of Florida, Inc.)
- I would prefer NOT to have my name listed as a Donor in the Beacon.

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Home phone: _____

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ADDRESS SERVICE REQUESTED

Spring-Summer 2008

Mission Statement

Dedicated to improving the quality of dying through education and advocacy, thereby empowering all citizens to make and carry out their own end-of-life decisions. We affirm the individual's dignity and free will throughout life, including the freedom to hasten death under certain circumstances.

*Pass this newsletter on to your physician as well as interested friends who may want to join us.
If you would like additional copies please send request to
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*If you no longer wish to receive this newsletter,
please contact the president at 800-849-9349 or HemlockFL@aol.com.*