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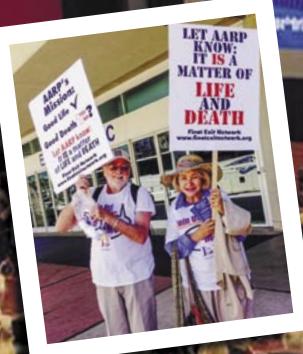
VOL 13 • NO 3

FALL, DECEMBER 2014

SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

OUBLE ISSUE!

PROMOTING DEATH WITH **DIGNITY:** background, Final Exit Network hosts the World Federation Conference 2014 in Chicago; inset, Final Exit Network members demonstrate at the AARP conference in San Diego.



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Final Exit Network From San Diego to Chicago

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ORLD FEDERATION CONFERENCE 201 WORLD FEDERATION OF RIGHT TO DIE SOCIETIES 2011 BERNIAL CONFERENCE I SEPTEMBER 17-21, 2014

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From San Diego to Chicago

Final Exit Network members joined together with two major events designed to empower and facilitate the conversation on right-to-die issues, first in San Diego and then in Chicago at the World Federation of Right to Die Societies' Biennial Conference 2014.

The 20th World Federation of Right to Die Societies meeting in Chicago swept the media.

On opening day, the *Chicago Tribune* featured a half-page article. *National Public Radio* interviewed Ms. Veronique Hivon, the legislator who had sponsored the magnificent new death-with-dignity law in the Canadian province of Quebec. *CBS Radio* interviewed Derek Humphry, and Final Exit Network member and Hemlock Society of Illinois President Ed Gogol appeared on the *Chicago Tonight* public broadcasting TV show. Also providing news of the event were Robin Marantz-Henig of the *New York Times*, Sandra Martin of the *Globe and Mail* in Toronto, Canada, and Tone Stockenstrom of *The Humanist* magazine. Both Robin and Sandra are also in the process of producing books on choice in dying.



Frank Kavanaugh, PhD WF Conference Committee Member in charge of media

In all, information on the conference went to some 50 media, medical and governmental organizations in the U.S., under the banner of *Final Exit Network*. Many of the delegates present, such as Pascal Landa of France, have authored works for readers in their home countries all around the globe.

- Frank Kavanaugh [Who, I'd be willing to bet, made those contacts happen. Ed.]

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Physician and writer Lewis M. Cohen left me a note at the conference requesting an opportunity to do a telephone interview for a book he's writing, "in which "FEN features prominently". The interview is scheduled for October 9, '14.

- Wendell Stephenson, President of FEN

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On a "Chicago Tonite" program, Wednesday, 9/24, I had the opportunity to advocate for our cause and for legal and ethical change right here in Illinois. The clip is permanently available on WTTW's website: http://chicagotonight.wttc.com/2014/09/24end-life-decisions

- Ed Gogol, Chair, Hemlock of Illinois

• • • • • •

It was a truly remarkable world conference, largely due to Faye Girsh on the program side and Julia Hanway on organization. It went like a clock!

Two things stand out in my mind:

- 1. For the first time, a world conference that dealt with the nuts and bolts, the down-to-earth aspects, of choices in dying. None of the high-falutin' philosophical waffle that used to be so prevalent in past conferences.
- 2. The great-hearted spirit, cooperation and conviviality amongst all the delegates, contributing so much to the pleasant atmosphere.

Congratulations!

- Derek Humphry, ERGO (conference speaker sponsor, NuTech)

World Federation Conference continued on page 12

EDITOR'S NOTE

DOUBLE ISSUE Fall 2014

Three major circumstances necessitated this double issue. The first was a momentous event: the historic conference in Chicago of the World Federation of Right-to-Die Societies, hosted by FEN. Second was the rejection by AARP of both our ads and our staffing a booth at their convention this past summer. So we had a large amount of timely material to bring you. The third event was death of my husband of 8 months (after 8 years together) and its devastating epilogue that rendered me less than functional.

You, our loyal member-readers missed two "normal" issues, summer and fall, and this catchup edition reflects my gratitude for your patience and support.

– Lee Vizer

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WORLD FEDERATION CONFERENCE

A SPECIAL THANK YOU TO:

Hemlock of San Diego - conference bag sponsor; Linda Banez - conference folder sponsor; and Final Exit Network and Hemlock of Illinois for all the outstanding members who volunteered their labor throughout the conference!

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for their generosity that made the World Federation Conference 2014 such a success.

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Fall Newsletter, December 2014

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In front of the San Diego Convention Center, above, clockwise, Faye Girsh and Fran Shindler; Faye and demonstration organizer, Marty Seidenfeld; Lee Shadle, and top center, Judy Miller volunteering for Hemlock of San Diego –all spent long hours with many other FEN volunteers from around the country on the demonstration line!

AARP's Mission:

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AARP's Mission: Good Life V Good Death

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AARP & FEN: The Opening Volley

[Our members erupted at the news that AARP had rejected a booth for us at their convention and refused consistently to publish our ads. Janis Landis suggested an e-blitz inspiring our members to email AARP and voice our displeasure. Below left is the blitz letter, a collaboration between Janis and Lee Vizer.]

FINAL EXIT NETWORK

FEN has had an unhappy history with AARP. First, we "don't meet their policy guidelines." Then, they allegedly "don't have a policy; they'll establish one this year." Rubbish. Their current policy is clearly evident in their repeated rejections of us. AARP, the iconic organization for allegedly furthering the well-being of its members, features "inspirational" and chirpy stories about over-50 celebrities. Skiers at 60. Ageless beauties, faces lifted. People with fame, money, and health. Nothing "heavy," i.e. real.

Booths burst with commercial enterprises: vitamin supplements, time shares, fitness equipment, all being hawked at "the good life" that apparently has no discussable end. In contrast, Final Exit Network provides elsewhere at its booths priceless information, free: Booth-visitors learn that options for self-deliverance exist, that dying need not be accompanied by suffering.

AARP members joined at 50, maintained Medigap and long-term-care insurance and now lead different lives. But AARP's beloved Boomers face death too. Their parents and grandparents need informed offspring to help them through their own crises. Meanwhile, AARP is stuck at 50+, and their loyal members face the crisis of their lives without the support of their professed "ally."

You FEN/AARP members reading this, let's bombard them with emails. Let them know you resent their rejection of Final Exit Network's presence at their conventions. Insist that they revise their policy.

Please send a copy of your communiqué to FEN's Newsletter Editor, Lee Vizer: lvizer@verizon.net.

[Close to 70 letters were received! Our members came through!]

Roughly alphabetized, our writers were Polly Amrein, Frank Anders, Nancy Jaicks Alexander, Ellen Azorin, John Abraham, Eleanor Aronstein, Mr. and Mrs. Bean, Misha Bearwoman/Metzler, John Braden, Huck DiVenzio, Nicole DiLorimier, Bright Dornblazer, Carol Dockson, Eldred Erdman, Dee Evers, Sally and William Feutz, Valerie Friedman, Barb & Paul Gerhardt, Judith Hinds, Tara Hands, Wye Hale-Rowe, Vern & Margaret Herzog, Ann Helms, Joseph Itiel, Christine Johnson, Eric Johnson, Frank Kavanaugh, Judy K, Mikel K, Wayne Kinzie, Lorraine Karmal, Margaret Lehto, Lois Lineal, Janis Landis, Rev. Edward Morgan III, Damien Miano, Elizabeth Norton, Harold Parker, Liz and Bob Paterson, Sue Reynoldson, Sally Rosoff, Johanna Sayre, Nicole Sharpe, Peter Smolka, Joel Shoenberg, Victor Schwartz, Joan Sophie, Judith Stephens, Ernie Smith, Monique Signoret, Rima Schulkind, Linda Sprengaler, Theodore Sherboy, Erica Twitchell, Lee Vizer, Jerome Weinert, "husband and wife," many who chose to write anonymously.

[If your name belongs here and is not, let me know. And please forgive any misspellings.] AARP IN SAN DIEGO continued on page 6

AARP IN SAN DIEGO

continued from page 5

AARP: An Insider's Perspective

AARP and I go back a while. For eight years, as board member of a national consumer organization, I worked with AARP on three levels: national, regional, and state. I was well acquainted, also, with a member of its national advisory board.

I learned how incredibly bureaucratic AARP is. All their speakers were carefully vetted to in-



sure that all comments would likely agree with their policies. Once, I addressed an AARP regional group in Dallas on the narrow topic of prepaid funeral insurance, about the time I testified before the Senate Special Committee on Aging on the same subject. AARP's representative kept her

Lamar Hankins

distance from any of the others, so that AARP's position would remain uncompromised by the views of the other panelists, though some were essentially identical!

AARP is hugely image conscious. National policy controls all speech and behavior in their state and regional offices. So, quite likely, AARP doesn't want to be connected to Final Exit Network in any way, even tangentially, because AARP has no official position on physician-assisted dying or hastening death by one's own hand. They may never formulate such a policy until the issue ceases to be controversial; the national organization seems incapable of initiating decisions about issues based on constitutional rights unless the issue has been completely settled. For many years I worked closely and cooperatively with the state-level AARP office, but their own staff could not be involved because of national policy.

AARP is hardly a leader among nonprofits in the areas where FEN is focused. It is more of a moneymaking corporation than a nonprofit, with affinity agreements with insurance companies, cellular services, endorsements, acceptance of commercial advertising, and other profitable efforts. AARP could be a national leader on many issues that concern seniors, but it is preoccupied with appearing nonpartisan. When the Medicare Part D drug benefit was passed in 2003, AARP would not stand up for the interests of its members by lobbying against the insurance industry's control of the program, nor the position that Medicare should be allowed to negotiate prices with the drug companies, as the V.A. does. AARP's coziness with the insurance industry (it endorses a Medicare Supplement program) and the drug companies took precedent over representing its constituents.

Those affinity relationships make them lots of money, but not much of a reputation for sticking their necks out for needs of Americans of any age, including seniors. Otherwise our Social Security benefits would not be taxed so heavily that most of us pay twice in federal taxes what we would otherwise pay. (Social Security benefits began to be taxed in 1983, in spite of an original promise that that would never happen.)

AARP does much good work, but it is not the advocate for its members nor the protector of retirees that it professes to be.

– Lamar Hankins

FEN Makes Significant Waves in AARP Drama

We did ourselves proud at our protest aimed at AARP at their conference in San Diego on the weekend of Sept. 3-5/ 2014, returning home with personal satisfactions and experiences with strangers that enriched our current moments and will likely produce considerable future buzz.

Let's look first at a tangible measure of the protest: its cost-effectiveness. If AARP had OK'd a booth for us in San Diego, as we had requested, that booth and its peripheral items would minimally have cost us \$3000. Add to that the costs of hotel room, meals and travel for at least two board members, probably more. Figuring conservatively, that would bring us to a total of \$4000, easily.

So what we paid to run the protest was about equal to what we would have paid to run the booth. But the similarity ends there. The benefits extended way beyond money!

The protest brought us dramatic press coverage that we would never have gotten from a booth! During those press reports we likely got our name before many people—who otherwise wouldn't have known about us—during just a day and a half of media presentations not seen since the showing of "The Suicide Plan."

We made personal contact and talked face-toface with hundreds of people—probably many more than if we had had a booth, as the 20-odd volunteers paced outside, walking miles up and down the sidewalk outside the convention



center. Those stalwart soldiers in the field reported that almost all who approached were receptive to our desire to have a booth and advertise ourselves in AARP publications, that many were very supportive to our cause in general, and few were genuinely hostile. (Those I met personally in that last category were, to a person, driven by religious belief.)

The protest also galvanized more volunteers from the area than would have been interested in simply minding a booth. What a difference it made in the energy level of the participants!

It was quite an exhausting effort, however, and all the volunteers who participated are to be highly commended. Marty Seidenfeld especially.

Some of the doughty volunteers who showed up could not walk much, but that didn't deter them from showing up in our T-shirts, holding a sign, and passing out brochures. It was inspiring to see our volunteers' support for us and dedication to our cause.

You've heard me say this before, and this experience was one more reinforcement: Seeing and working with such inspired, dedicated, warm and compassionate people is the best thing about being president of Final Exit Network.

- Wendell Stephenson

* * *

Putting it All Together

Members and other readers, you've already read how this event germinated into a major undertaking. We in FEN were tired of being rejected by AARP in their publications and at their conventions. The board decided we should take some action. Our people were enraged when they learned of it via a strong email concocted by Janis and Lee, requesting that they write and "raise a little hell." And Wendell suggested we stage some sort of protest at AARP's convention, asking me to organize and facilitate the event.

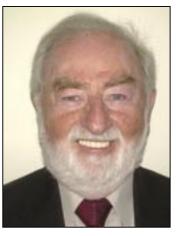
Many people participated in planning. Janis, Julia, Erica and I, with input from others, designed a T-shirt for our protesters to wear and developed a handout to give to AARP passers-by.

To have a real impact, we'd need some means of attracting the conventioneers' attention. We decided on pickets, large, colorful, pole-mounted jobs. Howard Finnecy, our board member and San Diego resident, oversaw the printing and mounting of the signs onto sticks.

An email went out to local members telling about our picketing plan and soliciting volunteers. We had a great response: 25 people showed, all fired up. All agreed to spend at least 2 hours each, pacing in front of the convention center, carrying a picket

sign and distributing literature. Many contributed considerably more than 2 hours. Wendell, Fran and I were there all three days, picketing continually each day.

Most conventioneers were shocked at AARP's rejection of our participation. Many—and this surprised us—were quite negative about AARP but belonged for



Marty Seidenfeld

the perceived discounts on various goods and services, recognizing that AARP is primarily a marketing organization.

When we described FEN and its mission, we heard many stories of a spouse or parent or other loved one who had suffered needlessly. They understood the importance of our mission and supported us. Many said they would check out our website and consider joining.

There were a few negatives, mostly religious people who believed that we were interfering with issues that belong in god's hands alone. One woman told me angrily that AARP supported us, by backing President Obama in his decision to pay doctors for time spent in end-of-life discussion. She didn't *AARP IN SAN DIEGO continued on page 8*

AARP IN SAN DIEGO

continued from page 7

like how we were "encouraging people to die." She was angry and refused to listen, walking off in a huff.

My most moving encounter occurred with a man 30-ish, accompanied by his wife and young child. Too young to be AARP members, they were just hanging out outside. They asked about my sign, and when I answered, the man became overwrought, stating he was suffering from testicular cancer and was thinking he'd soon be dead. I listened intently, for which he seemed grateful, and when I told him about FEN he became quite enthusiastic, gladly accepting our handout and stating that he would look up our website.

I believe our impact on AARP members was quite significant. We all had interesting stories to share with each other.

We also garnered a lot of media coverage. Frank Kavanaugh did a terrific job of notifying the media about our protest. Fran and I were interviewed by the local NBC media. AP picked up the story, depositing it in several newspapers nationwide. San Diego's newspaper wrote a very positive story about us, stating that AARP treated us like we were the skunk that showed up at their picnic. It created quite a buzz.

All in all, our own excitement was proof that our protest was quite successful. A lot of people heard about us for the first time, as we spoke and listened. Our efforts cost us about \$5000, and we got more bang for our buck than if we had actually rented an exhibit space inside that convention!

- Marty Seidenfeld

P.S. Getting things done through committees is always difficult. When the committee comprises people all over the country—most of whom I barely knew, if at all—then it's a real challenge. But everyone was so cooperative, so willing to contribute, so eager to help, that all was made easy. I am in awe of the degree of ego-less cooperation of so many FEN people. It was truly a pleasure and an honor to work with them. – *Marty*

* * *

I can surely sympathize with the protest's being tiring, but it worked out great. A big thanks to all of you. Certainly more bang for the buck than a booth and a feeling of having made a difference for those who were part of it. Well done!

– Frank Kavanaugh

* * *

The Pen Is Mighty: Our Members Write AARP

The Feb/March 2014 issue of *AARP Magazine* once again featured positive, upbeat stories about attractive, aging people. AARP's universe is populated with folks who are productive and mentally acute until they die peacefully in their sleep without illness or pain or any of the indignities of aging. A very attractive fiction. AARP refuses to address the realities of aging, publishing stories that are not pretty: how to cope with sickness, pain, and loss. I am proud to be a lifetime member of Final Exit Network, working for the probability that my dying will be my way and that suffering will be minimized.

AARP Magazine is nothing more than People Magazine Lite for the 50+ reader.

– Valerie Friedman

You say guidelines have not been set. How disturbing. AARP purports to be aimed in behalf of those over 50, yet you have "not established a policy" on what is literally a matter of life and death?

* * *

You seem quite cavalier about it. Involved in the mix are the elderly, often frail and incapacitated; the plight of their relatives and caregivers; religions and belief systems and how those influence the patients facing death; the medical professions; Big Pharma; traditions and social views; the role of power over the dying person.

People are living longer and dying longer. Alzheimer's and dementia are almost pandemic and growing. But AARP "doesn't have a policy." You have endless time to discuss this. But people suffering in their beds have no such intellectual luxury. And then there's the profit motive . . .

* * *

– Johanna Sayre

I'm a man, 80, a member of both AARP and Final Exit Network. Your deliberate avoidance of death and dying smacks of ostrich behavior and does your members a great disservice. 100% of them will die. So when a non-profit organization like FEN, whose sole mission is to alleviate intolerable suffering, approaches you for a booth, where is your welcome? Your members have a whole gamut of concerns and interests. It is folly to dictate from headquarters which views you will allow.

– Joseph Itiel

* * *

The more I see of the many pages of ads and articles about "younger old folk," the more turned off I get. – *Margaret Lehto*

A recent heading in a local paper referred to a birthday celebration for so-and-so, "One hundred years young!" Barf! - *Anonymous*

AARP, in addition to talking to FEN, perhaps your prep for revising your out-of-step policies might be to ask your own members. Poll your people, if you have the courage. The results may surprise you. – *Janis Landis*

In 1969 the American public was awakened by the pioneering and outspoken truth that we are all terminal. Elizabeth Kubler-Ross, MD, in her seminal work, *On Death and Dying*, encouraged realism about our mortality and challenged us to grow up. That challenge gave birth to the hospice movement in this country, and dialogue about **how** we die became part of our public awareness.

Final Exit Network is a strong proponent of an individual's right to choose how they die. It is an all-volunteer national organization addressing these desperate issues with knowledge and support for all involved: family, friends, and caregivers. AARP, how we die is a major civil rights issue. From your very inception you have supported the rights of retirees and seniors. In this "final right," your members need you most. Your publication should be bursting with information and viewpoints on this most universal experience.

It's been 45 years since Kubler-Ross, and the suffering continues. Isn't it about time?

- Nancy Jaicks Alexander (Mrs.) * * *

I remember being 50. Best time of my life: newly remarried, in great shape, with two careers I loved, wonderful kids and siblings, looked maaahvelous.. My myriad joyful and healthful activities defined me. Today, considerably older, I define myself by the "used to's": those activities *I used to* love and excel at.

Your chirpy messages imply you can do anything you want if you get inspired and have the right attitude. I mumble with considerable disgust, "Right! All I need is foot transplants!"

Even your Boomers, all 76 million of them, your chosen target readers, are not all gorgeous and healthy, and none is immortal. Many hurt. Every birthday reminds them that they're another year closer to their own mortality. As caregivers for parents

Skunk at the AARP Garden Party



and grandparents, many have already seen the writing on the wall, first-hand. They know that bungeejumping and skiing don't solve everything.

So how about easing up on the "chirp factor"? How about re-embracing your original core group, loyal members like me who pay for AARP's Medigap and long-term-care insurance and now are off your radar? How about letting Boomers know that several organizations exist that aim to make them the rightful determiners of their own end of life? That AARP, their no-longer-phony "ally for real possibilities" will be a *genuine* ally, not only for possibilities but for a more hopeful form of *inevitability*, alleviating their deepest fear that some other person or institution will decide their end?

Start with us. We are neither the largest organization nor the wealthiest. But we are unique in ways that matter. We are Final Exit Network, and I am proud to be its newsletter editor. – *Lee Vizer* www.finalexitnetwork.org.

P.S. In September we hosted a global happening: the 20th Biennial World Federation of Right-to-Die Societies in Chicago, September 17-21, 2014.

AARP IN SAN DIEGO continued on page 10

AARP IN SAN DIEGO continued from page 9

We invite AARP to staff a booth in the future and to meet some of the most exciting, courageous speakers in the world.

* * *

We are all 50 for one year. Age and illness and the road ahead are the biggest crises we face. Where is our "ally for real possibilities"?

– Eleanor Aronstein

Elitist: my long-term perception of AARP. AARP is currently more contrary to my values than I could have imagined. Your rejection of FEN smacks of religious/political influences controlling your editorial decisions. Final Exit Network exists to provide informed choice at end of life. Even in my state of Oregon, where we have the benefit of death-with-dignity legislation, still the 6-month required "terminal" designation excludes many individuals suffering from long-term horrors such as ALS, cancer, and many others.

Please send me, as an AARP member, the policy guidelines that prohibit you from welcoming FEN into your events and publications.

– Judith Stephens

* * *

Attached is a copy of a *Wall Street Journal* article indicating the huge current interest in the formerly taboo subject of dying. "Death Cafes" and other peer social groups that discuss death and dying are booming. You, AARP, are out of the trend, your head deep in sand. I hope your sad condition results from mere myopia and not any religious bias of your leaders. You are already so far out of reality that you are becoming irrelevant to the Boomers, who want to lead their lives their own way, including how they pass on.

– Ernie Smith



Either all seniors are smiley, healthy and active or AARP simply portrays them that way. Though many AARP members endure an unbearable physical current life and an even worse future, AARP's behavior shields them from sources that might provide comfort and peace of mind. AARP would better serve its members by compiling and airing such references. I'm a member of Final Exit Network and was about to join AARP, but its avoidance of deathwith-dignity issues is unacceptable.

– Huck Divenzio

As a grateful, contributing member of FEN, I am disappointed at AARP's disconnect with the organization. Aging is not only about cruises, golf, and good times. It is also about dealing with the inevitable restrictions placed on us during our declining years: illness; finding the means to provide costly, needed help; a peaceful end of life. Your magazine does not speak to me. You have a good deal to learn about the organization you so consistently reject. In doing so, perhaps you will all experience the peace of mind that FEN engenders. – *Eldred Erdman*

A long-term AARP member, I take strong umbrage at your refusal to help FEN spread its message in your publications and conventions. Publishing ways to improve quality of life is worthy of support, but your message skips the other side of the coin. In good health at 88, I am showing signs of dementia. Entering "that good night" in ignorance is an invitation to disaster. – *Bright M. Dornblaser*

* * *

* * *

I have held dual membership in the past, but only FEN currently. FEN speaks to my life now, where AARP does not, though I still support it. Likely, I will never need AARP again but will, in all probability, definitely avail myself of FEN's services. Currently it provides me with support and knowledge that help me with my loved ones when they need me most. AARP is only interested in my welfare when I'm alive and well, but my greatest need will be when I am less than well and declining. The universal fact of life is death. All else is unapparent to us. FEN has the courage to confront this singular but certain event openly, honestly, and with love.

If AARP becomes relevant to my life again, I might even rejoin. – *Wayne Kinzie, Ph.D.*

* * *

AARP's exclusion of Final Exit Network comes as no surprise to me. They refused me "any medical coverage through their program," just like all other health-insurance companies, for over 20 years.

AARP REPLIES

The following two letters are the responses AARP sent out to about 40 FEN writers, under many different signatures but with identical text.

"AARP's president has asked me to thank you for contacting AARP to ask why the Final Exit Network will not be able to have a booth at AARP's National Event where members will be discovering the <u>Real Possibilities</u> in their lives. We value feedback such as yours and we have taken note of your comments. It's my pleasure to respond.

"Although we appreciate the interest that Final Exit Network has expressed in exhibiting in 2014, at this time we have not yet established clear guidelines on right-to-die societies. Establishing guidelines for this type of category requires input from various teams. It is something we hope to do this year.

"I hope this helps to answer your question about our process for the 2014 member event. Thank you again for writing. If my colleagues or I can assist you in the future, please do not hesitate to reach out to AARP, your *ally for real possibilities.*"

The second form letter, sent to fewer people, was the brainchild of AARP's 'Product Development Team.' They were responding to what they thought was our request for a booth to display (and sell?) our 'product,' suggesting that we submit our proposal to their website, and if AARP had any interest in what we were selling, we would hear from them. (Had they even read our request at all?).

"It is the goal of AARP Services to deliver products and services that significantly enhance the quality of life for people aged 50+. AARP has millions of members, and the products selected are prioritized based on having the broadest appeal and providing the greatest value to our membership.

"Your dedication and commitment to serve the 50+ marketplace is (sic) important to us. Thank you again for your interest."

Sincerely, Phillip Bailey Member Relations None of them believed that my pre-existing condition, multiple sclerosis, entitled me to a peaceful end. They are all about making money. That motive prevents their members with serious health problems from exploring the choice of a self-determined death. AARP might lose out on a few extra months or years of squeezing every dime out of a patient or a beleaguered family struggling to pay for prescriptions and procedures in an institution where the patient never wanted to go in the first place.

– Joanne Kissler

All of the admirable folks you feature in your inspirational articles created their successes by taking risks. AARP, what keeps you from stepping out of your own comfort zone and trying some risks of your own? Why don't you follow in the footsteps of your own revered role models? You have glued yourself to your outdated philosophies and will not un-Velcro yourselves, come hell or high water. Well, they are coming.

- (Name Withheld)

Hooray! The Boomers are taking over AARP! They have a reputation for getting what they want. And that may include a peaceful, legal death. 100 may be the new 90, but one thing about aging is that ultimately it leads to death. And many of those deaths will happen after people have been warehoused in nursing homes, after long years of dementia, grueling attempts to beat cancer, or gradual decrepitude. Along came Final Exit Network, providing information and support to its members who are considering a peaceful, hastened death. But AARP refused to allow this 10 -year -old non-profit to have a booth so it could let the Boomers know that there IS a way out when the perpetual joy, energy, and enthusiasm of aging have petered out. Network supporters demonstrated at the Convention Center in San Diego to protest this exclusion. Maybe the attendees will give some thought to the kind of death they want. Certainly AARP should.

- Faye Girsh



* * *



With thanks to our photographers: June Miller, Judy Miller, (unrelated), especially to Frank Kavanaugh, Richard Côté, and Nick Sheridan

ERGO has generously contributed as a major sponsor of the World Federation Conference.

What a Conference We Had in Chicago!

By Faye Girsh, 2013-14 President, World Federation of Right to Die Societies

he 20th Conference of the World Federation of Right to Die Societies (WF) was held in Chicago September 17-21, 2014 – and was a fabulous success. Over 230 attendees from 24 countries met at the lovely and spacious Embassy Suites Chicago Downtown Lakefront. [Conference host Final Exit Network is a member of the WF.]

Wednesday night started with a three-hour reception. Volunteers from Hemlock of Illinois had installed flags in the hall from each member country. What a feeling, watching the mingling of Israelis, Swedes, Canadians, South Africans, Australians, Colombians, Japanese! An official welcome led by Wendell Stephenson, president of Final Exit Network, and me, president (now "past") of the World Federation, launched the event.

Pictured during the Gala awards ceremony, from left, incoming WF president Ron Plummer, WF communications director Rob Jonquiere, WF president Faye Girsh, Hélène Bolduc and Russell Ogden, Faye Girsh and Derek Humphry.





Visit www.worldrtd.net for links to speeches, Visit www.worldrtd.net for links to speeches, video's & the latest WFRTDS news. www.finalexitnetwork.org 13



Wendell Stephenson, WF Conference Committee Chair spent a year and a half spearheading the committee and overseeing all planning stages



Frank Kavanaugh spent months formulating and executing a global media plan, guiding media experts through the oftenunknown territory of the right-to-die movement.



Linda Banez was in charge of helping proof media, arrange housing and roommates, as well as preparing on-the-ground travel directions, detailing every aspect of travel guidance for attendees in Chicago.



Howard Finnecy was responsible for shepherding the opening Wednesday Night Reception, that turned out to be a great opportunity for meeting new friends and renewing old acquaintances.

The Team That Made It Happen

A Recap of the Conference

By Faye Girsh, WFRTDS 2013-2014 President

he World Federation of Right to Die Societies (WF), was founded in 1980 and comprises 52 right-to-die organizations in some 28 countries. Membership is extended toward groups rather than individuals, but that may change. We have an e-newsletter and are happy to include all interested individuals who have email (send me your name and email address). And an informative website is accessible to all: www.worldrtd.net.

The conferences are biennial. Final Exit Network (FEN) volunteered to host for 2014, with ERGO as co-sponsor. I arranged the program, working closely with our experienced, creative and tireless phenom from FEN, Julia Hanway, to create one of the best meetings ever.

Video recordings from the conference are free and available at www.wfconf2014.com.

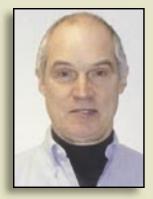
On Thursday, September 18, three days of programs began with a dizzying variety of top-notch choices. Decision-making proved difficult; we wanted to be everywhere! Laura Belli presented an update about Argentina. Boudewijn Chabot discussed an elderly man wanting to die. Kathryn Tucker, former legal director for Compassion & Choices, gave her auThe latest figures presented to the Final Exit Board at their November meeting by the volunteer meeting planner Julia Hanway: the World Federation Conference 2014 came in under budget, in spite of the fact that attendance was far over the anticipated number.

dience a systematic analysis of legal approaches that might encourage successes. Sean Davison of South Africa wowed us with a stirring video presentation.

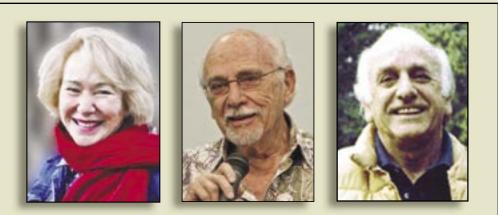
The sample above is just a tease: 4 out of 10 thrilling audience experiences involved us all day and gave us more to discuss than we had time for, as we met friends in the halls during breaks and rushed to fill them in, fast!

Lest our readers think that all we did was enjoy ourselves-*heaven forbid!*-I reassure you that productive business meetings took place too. World Federation (WF) delegates met to vote on the new WF board and learn about reorganization plans for this international organization. And FEN, our host organization, held its annual board meeting on the day before the WF conference officially started.

WFRTDS continued on page 16



Richard Mangeot worked diligently tracking our expenses and reporting on the moving target of our budget. We ended up under budget and were about 150 attendees over our original projections.



World Federation Conference Speakers Commitee

From left, Faye Girsh spearheaded procurring speakers, producing the schedule, and finalizing plans, working from California to pull together the global network of right-to-die societies in Chicago; Dick MacDonald was especially helpful with advice and coordination of the Canadian contingent and arranging for Mme. Veronique Hivon's attendance; Derek Humphry of ERGO, sponsored NuTech and the legal presentations of FEN's general counsel Robert Rivas, attorney Kathryn Tucker's presentation, as well as Chris Docker's NuTech program on Saturday.



Dawn Pollock, Final Exit Network's Operations Manager, spent months working with the committee helping to facilitate plans.



Erica Twitchell, Final Exit Network's Office Manager manned the welcome desk at the conference, troubleshooting and working to make attendees comfortable and happy.

Below, WF Conference host Final Exit Network president Wendell Stephenson and Faye Girsh welcome attendees.

Above, volunteer meeting planner Julia Hanway was awarded a plaque for her work planning the conference.



Delegates from left, /Ron Plummer, Monaco; John Hunt, Australia; Ian Wood, Australia; George Eighmey, U.S.; Aycke Smook, The Netherlands



WFRTDS continued from page 15

Friday and Saturday, two simultaneous programs ran all day with panel discussions, audience participation and fascinating speakers. They dealt with the following, and more:

- How to extend physician aid in dying for the terminally ill (as in Oregon,Washington and Vermont) into other areas;
- Whether to explore going beyond the criterion of terminally ill to include long-term sufferers, the elderly, those dealing with psychiatric issues, couples, and dementia;
- To consider non-medical procedures (such as the methods recommended by FEN).

In Breaking Barriers, speakers discussed under-

served populations to which serious consideration is being given in the Netherlands, Belgium and Switzerland. An excellent presentation on couples' joint exits was made by Dr. Erika Preisig, head of LifeCircle in Switzerland.

Next door's group explored expanding legal DWD in other countries. Chaired by Wendell Stephenson, some speakers

were Robb Miller, George Eichmey, Peter Warren, and Jean Luc Romero. From Quebec, young parliamentarian Veronique Hivon shared her role and success in passing the Medical Assistance Law.

NuTech (new technologies in self-deliverance) attracted Dr. Chabot from the Netherlands and Chris Docker from Scotland, both recent authors on self-deliverance methods (see amazon.com) Derek Humphry, author of *Final Exit*, chaired. Dr. Gustavo Quintana, from Colombia, shared a video of the voluntary euthanasia of two of his patients, while

Faye Girsh presents an award to Michael Irwin, which is accepted on his behalf by Liz Nichols, (UK).

tacular downtown architecture.

Look for more detail in the *World Federation Newsletter*, which WF and all FEN members will be receiving this time. (Interested in subscribing? Let me know.)

We were thrilled to be part of this historic, enlightening, and wonderfully social event. Here's to the next one: *Holland*, 2016!

- Faye Girsh, Past President of the World Federation, Senior Advisor, Final Exit Network fayegirsh@msn.com.

another room held a panel on successful organizations, headed by Wanda Morris, and another panel on how doctors would like to die (mostly by lethal injection!)

Thursday night, Dr. Rodney Syme presented to an enthusiastic audience how to deal with advanced dementia.

Friday night was the climax of the convention: a spectacular Gala Awards Dinner on the 92nd floor of the John Hancock Building, providing a shimmering, panoramic view of the city. The World Federation honored Dr. Michael Irwin (SOARS), Veronique Hivon, and Dr. Rodney Syme. A nontraditional Lifetime Achievement Award was made to

Derek Humphry, founder of the Hemlock Society and author of *Final Exit,* "for contributing so much, so long, so tirelessly, and so courageously to our right to a peaceful death." The scene was beyond gorgeous, the festivities, touching.

Sunday morning provided a total change of pace: a boat ride down the Chicago River led by an expert on Chicago's spec-



A special thank you to our volunteer videographers who helped preserve a record of the WF Conference 2014: video organizer Nick Sheridan and colleagues: Winnie Downes, Randi Fiat, Ellie Kincade, Edward Schneidman; program volunteers Pascal Landa and Diane Schlair, break timer Elva Schneidman; and session timer coordinator Joan Sophie, among many others. Thank you!



How Would You, a Doctor, Wish to Die?

Dr. Richard MacDonald Presenter, World Federation Conference 2014

Most humans,

doctors includ-

ed, tend to con-

cur with Woody

Allen's position:

"I'm not afraid

of dying. I just

don't want to

be there when it

happens," agree-

ing that it's not

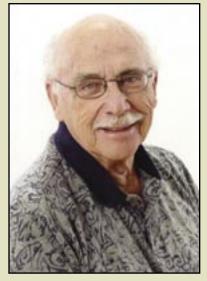
death they fear

as much as how

they get there.

They often don't

hear that question frequently. I applaud that curiosity. Everyone needs to consider that death is an equalopportunity event, the ultimate end for all of us. But non-medical professionals oftenignore the likelihood that death will come after prolonged and grueling medical interventions.



Dr. Richard MacDonald

know that options exist. And "getting there" takes longer and longer, due to science's "conquering" of infectious diseases, "new and improved" medicines and procedures. We die later than we used to, by which time there are more impediments to true quality of life. So, ironically, we physicians, though prevented from hastening your dying, are permitted to keep you miserable for prolonged periods of time.

Back to the question. I don't need to think long about it. I already have done so, with my presence at deaths of my patients, loved ones, parents, siblings, and friends. I stood by helplessly for 13 days, watching my oldest son die following an accident, but I learned much about what medical technology can offer. I learned that, in the urge to save a life, the physician may not consider what "success" after the battle would feel like to the patient. Is success total dependency on others? Would the physicians themselves want to live in the physical state that would follow their heroics?

Those introspective questions remain unasked because medical institutions of learning do not address them. Most specialty residents spent not even a week in nursing homes or hospice care.

Of all the exposure I've had to death and dying, the most convincing education occurred for me by contact with those courageous individuals who, suffering, were determined to hasten the dying process. They taught me a lot about living, too.

The choice to die is not an impulsive decision, as happens sometimes in a suicide after some devastating loss or predicament. My lay mentors were now self-educated experts who had gathered all the information they could, through questioning their doctors, their friends, and that marvel of modern information; the internet. What course will my disease take? What will my quality of life be in the future if I let nature rule?

Though relatively small in numbers, those who choose the exit route are nevertheless large in need, and their dilemma and courage in the face of it warrant serious attention.

When exiting was the decision, I and their loved ones noted a dramatic difference in their outward mien and appearance. An East Coast woman once called me urgently, requesting a visit, accompanied by a local volunteer. She was concerned how she could be in charge if she went ahead with her plan. She could still walk and drive, in spite of an advanced malignancy in her abdomen which had been treated with radiation, surgery, and chemo. A recurrence prompted the question of whether more therapy might be fruitful. A few months, she learned, would be all that she could buy. With the memory of side effects still in her brain, she nixed the resumption of treatments. She feared being institutionalized and losing her independence. She wanted to die at home, soon, to avoid hospitalization.

As a FEN member, she knew an option that was peaceful, sure, and virtually guaranteed to succeed. She and I and her volunteer discussed her chances over wine and cheese at her condo. Her fear was that she would wait too long. She was apprised of the supplies required, was grateful for the information, and promised to call us soon.

Two weeks later, her volunteer relayed the news that an unusual calm had come over her since our meeting. She said, "Now I feel so at peace, knowing I have the means here in my home, so that I can proceed any time I want to. It's made me decide to live longer. I can visit my only remaining relative and his kids, whom I adore but haven't seen for a year. Nephew is going to transport me- I've decided I'm capable of travel- so he's driving me the 300 miles round trip so I can stay a day or two. I hope you'll forgive my postponing the chosen date." Forgive? I was so pleased.

Three months later, another call came. Her symptoms had progressed. We arrived and were told, "My time has been so embellished by my being able to make that trip." Her nephew, aware of the circumstances, chose to be with her and us when she ended her life. She appeared relaxed and ready and said she had been "waiting for" that day. Wine and cheese were on the table, photo albums around the room for our- and her nephew's-perusal. He had collected some of her favorite music which played softly as they reminisced, and she shared some of the happiest recollections of her life with us, laughing at some which she knew would surprise- and shock- her nephew.

So how would I want to die? Not like Woody Allen. I want to be there. I hope to have a warning and time to plan. I would die from an overdose of barbiturates. Being fortunate enough to be a physician, I have access to medications more available to my profession than to the public.

I want to say lots of goodbyes and express my gratitude. Maybe even mend some relationships. Before my last day, I wish to have a fine Living Wake, a wonderful idea that some clever predecessors had invented. There'll be good food, potent beverages including my beloved single malt Scotch, laughter, stories and music, all mixed in with love. My children already have a list of photos and memories I want to share with everyone.

Perhaps before then there will be greater acceptance of the choice that we in the death-with-dignity movement so passionately espouse. Then those not in the medical professional will have the same rights and opportunities as those who are. Many of my colleagues feel the unfairness of our current advantage as neither ethically nor morally correct. All should have, if they choose, the humanistic right to control their own dying. We are working to create that change within own lifetimes.

By Dr. Richard MacDonald, from a presentation given during the WFRTDS conference, August, 2014





Left, Hélène Bolduc (Quebec) accepts an award on behalf of Mme. Veronique Hivon for her recent work in the Canadian parliament.

Above, attendees enjoyed the amazing view of Chicago from the top of the John Hancock Building. Below, a generous anonymous donor provided beautiful music by harpist Penny Courier for Gala attendees. By all accounts, the conference was a complete success, facilitating the death with dignity conversation throughout the world, allowing for forthright conversations and cross-cultural networking in a setting that promoted new and renewed friendships that will further our cause well into the future.

Thank you

to our donors, volunteers, and members for their important contributions!

To view selected videos of the conference, visit www.wfconf2014.com



Dying Autonomy

V oluntary assisted dying is a process of open discussion which has two purposes. First, it allows informed decisions by competent individuals to continue living with their doctors' support, so long as the person still has a life with real meaning. Conversely, if "living" means nothing but a descent into torture and misery, the doctor can prescribe oral medication at the patients' request, to be held aside or taken when conditions are right, in their own home, their own time, with whomever they choose to share their dying experience, accompanied by hugs and goodbyes.

I espoused the latter scenario on the basis of six medical end-of-life givens:

- Dying crescendos with intolerable suffering as death inches nearer.
- Some suffering will only end with death.
- Doctors have a duty to relieve suffering.
- Palliative care cannot and does not relieve all pain and suffering.
- Some patients do rationally and persistently request a hastened death.
- Doctors have a duty to respect patient autonomy.

What palliative options currently do exist in the face of those givens? The American Academy of Hospice and Palliative Medicine cited three: refusal of life-prolonging treatment (not an option open to many patients); voluntary refusal of food and fluids, which may likely result in slow dying with no mention of palliation for associated suffering; or the offer of "palliative sedation, even to unconsciousness." This is a process of titrated medication, controlled by the doctor, not the patient, which again may be lengthy and is usually associated with withdrawal of fluids.

It is a process that clearly leads to death, albeit slowly. Some palliative physicians have called it "slow euthanasia."

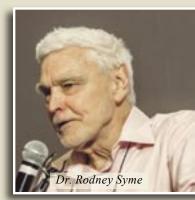
The slow titration approach to palliative sedation is free of legal concerns for the doctor; providing medication with the intention of relieving pain and suffering which foreseeably hastens death, incurs no legal problem. The AMA Code of Ethics supports this approach. **Presenter: Dr. Rodney Syme**, "Dying Autonomy," *Medical Journal of Australia*, 18 August, 2014

The palliative care problem stems from its philosophy, which states that palliative care neither prolongs dying nor hastens death. The patient may suffer a partial relief of suffering and a slow death to protect the moral interests of the physician. In whose best interests is the doctor acting?

The federal government is seeking submissions on the exposure draft of the Medical Services (Dying with Dignity) Bill 2014, which includes reference

to the rights of terminally ill people to seek assistance to end their lives. However, governments in Australia currently support palliative care, stating that it renders the option of voluntary assisted dying unnecessary.

That attitude ignores a significant problem: the not too occult religious philoso-



phy underpinning palliative care, 60% of which is provided by the Catholic Church in Australia. This, of course, puts much practice in a specific moral and ethical framework which may be anathema to the patients'.

Doctors who avoid or deny conversations with their patients about dying have several possible reasons. They are unaccustomed to that kind of honest intimacy. Some are ignorant or in fear of the law. Some have their own moral perspective that keeps them silent.

But patients often experience genuine relief in just being able to share their fear and concerns, and doctors will find that listening is a powerful balm for distress. (Flippant remarks do not constitute listening, like "Don't worry; I won't let you suffer.")

There seems no logical reason why a person, dying with unrelievable suffering, loss of meaning and control, should, by law, go to the very end of the line. Many patients say that they would like to die at the end of the day, as the sun is setting, rather than go in the dark night.

At a medical students' conference, I asked neophyte doctors to compare the two ways of dying, for a person who had fulfilled the six medical "givens."

Would they respect their patient's autonomy in this circumstance?

Review by Lee Vizer



[Excerpt] If you become paralyzed, refusing food and liquids may be your only option; yet the preparation and awareness needed for that method is considerable, and hardly to be undertaken when you find yourself incapacitated. Some methods have an "easy fail" rate . . .



[Excerpt] Perhaps you find yourself unexpectedly hospitalised, or in a nursing home or some other situation that doesn't allow you the privacy you need for helium. Circumstances can change suddenly with illness, stroke, or accident. Which methods could you manage should you be slightly delirious with pain?

Above and box at right: graphics and contents from Chris Docker's thoughtful 49-page publication. >

n Chicago, at the World Federation Conference, we audience members who were fortunate enough to attend the Nu-Tech presentation by Chris Docker, early organizer of Exit, were amply rewarded. The Saturday, September 20th program was sponsored by ERGO and featured a number of speakers. Chris Docker produced an extensive paper for experts and scientists outlining the research he did for his presentation at the World Federation Conference. The following paraphrases some of the riches in his position, garnered from a longer and eloquent paper: "Self-Delivery Methods and Dialogues."

INTRODUCTION

Developing Cooperative Dialogues Scientific method (Popper) Critique a method, not the origin Networking, Dissemination & Transmission

THE CHICAGO SEMINAR -IDEAS AND SLIDES

Self-deliverance philosophy Examining methods of self-deliverance Helium Ligature compression Fringe methods Starving one's body of food and liquids Hydrogen sulphide Firearms Plastic bags and drugs New ideas and suggestions for further research Solving puzzles Other avenues The moment of death

(Chris Docker © 2014)

A few essentials in his thinking are these:

- 1. In searching for new methods, using the scientific method, properly, is a given.
- 2. Researchers need to describe themselves not as the one with the answers but as one of those who are seeking answers, along with colleagues.
- 3. Aiming to see and share flaws that could create failure is essential to eventual success. The persistent examination of failures brings us closer to true effective-ness.
- 4. The "bandwagon tendency" is a no-no: "Everyone says it's right," or "Many are using it, so it must be good."
- 5. Scientists are aiming not to be infallible but to be less fallible.

With any new and promising method of self-delivery, an immediate challenge is to see that it is disseminated correctly. A fine method, improperly taught to the tutor or incorrectly utilized by the receiver, could spell disaster. Unintended consequences can be frightening. If a severely ill friend were to ask us, "May I read your self-help book on ending one's life?" we would likely say yes. But what if that friend, in her haste or poor state of mind, were to misinterpret, misread, or mis-perform the instructions and suffer a bad death? Even one such a death is not acceptable.

For example, we know that helium is a tried and true method whose instructions have been translated into other languages and other countries. But what happens if the translation is not true to the original meanings? Or the patient misunderstands the video? What happens, in an exit using drugs, if the patient "improvises" and deviates from the tested teachings? Errors have turned up: 1. The research sample was too small. 2. There was non-integration of the recipient organization of KSA's (knowledge, skills, and attitudes.) 3. Mental or physical infirmities infringed: the method was too complex, or there was a failure to anticipate problems.

Nu-Tech exists because there are always exceptions to any choice of method, and having a back-up is wise.

Check out Chris Docker's book: *Five Last Paths*, a summary of peaceful exit methods known today.

COUNTRIES REPRESENTED AT THE WORLD FEDERATION CONFERENCE

Participant/Speaker Laura Belli	
Dying With Dignity Victoria	
Christians Supporting Choice for VE	
Northern Territory Voluntary Euthanasia Society	AUSTRALIA
ADMD Association pour le Droit de Mourir	
dans la Dignity	
RWS	
Dying With Dignity - Canada	CANADA
Assn Que Becoise Tour Le Droit de Mourir	CANIADA
dans la Dignite	
Farewell Foundation	
AQDMD-Quebec	
Right to Die Society of Canada	
Farewell Foundation	
Collecif Mourir digne et libre	
PAC Dying with Dignity, Canada	CANADA
Fundacion Pro Derecho a Morir	
Dignamente, DMD-Colombia	
Friends At The End (FATE)	
ADMD-France	
Association Ultime Liberte	
AA Vivre SA Fin De Vie	
VEREIN STHD	GERMANY
LILAC-The Israel Society to Live and	
Die With Dignity	
Japan Society for Dying with Dignity	
Participant Asunción Álvarez del Río	
WFRTDS Incoming President	
Stichting de Einder, Netherlands	NETHERLANDS
World Federation of Right to Die	
Societies & RtD-E (representatives based in	
the Netherlands attended)	
NVVE	
End-of-Life Choice New Zealand	
EXIT	
Dignity South Africa	South Africa
RTVD / Sweden	
Lifecircle	
EXIT Deutsche Schweiz	
Dignitas	
VEREIN STHD	
EXIT-Deutsche Schweiz	SWITZERLAND
LifeCircle	
Hemlock of Illinois	UNITED STATES
ERGO	UNITED STATES
Compassion & Choices of Washington	UNITED STATES
Final Exit Network	UNITED STATES
Hemlock of Illinois	UNITED STATES
Hemlock Society of San Diego	UNITED STATES
Hemlock Society of Florida	UNITED STATES
Princeton Theological Seminary	UNITED STATES
UCLA School of Law	
PSDAmerica, Inc	UNITED STATES

UPDATES HEARING IN MINNESOTA • NEW FEN BOARD MEMBER

Legal Update: Minnesota

hearing is scheduled to be conducted on December 8 in Hastings, Minnesota on charges that Final Exit Network and two of its volunteer Exit Guides "assisted" in a "suicide."

A new judge, Christian Wilton, will preside. The former judge, Karen J. Asphaug, recused herself in September for undisclosed personal reasons.



The case has now returned to the trial court after an 18-month odyssey through the Court of Appeals and Supreme Court of Minnesota. In the wake of the appeals, the state's case has been crippled.

Judge Asphaug ruled in March 2013 that the Minnesota statute–which prohib-

FEN General Counsel Robert Rivas

ited "advising," "encouraging," or "assisting" in a "suicide"–violated the First Amendment. The statute, she ruled, may permissibly prohibit "assisting" in a suicide, but violated the right to free speech to the extent it prohibited "advising" or "encouraging" a "suicide."

Until her ruling, the State had intended to seek a conviction by proving that the Network, its former medical director, Larry Egbert, and a former case coordinator, Roberta Massey, "advised" or "encouraged" the 2007 death of a Network member in Apple Valley. The State, therefore, appealed Judge Asphaug's ruling and the proceedings in the trial court were placed on hold pending the appeal.

The appeals courts have affirmed and even strengthened the trial court's ruling in favor of the Network and its volunteers. At the hearing in December, the new judge will rule on certain pretrial motions and schedule a trial, probably sometime in mid-2015.

The Network corporation and Dr. Egbert are each charged with assisting in a suicide, aiding and

abetting to assist in a suicide, interfering with evidence at the scene of a death, and aiding and abetting to interfere with evidence at the scene of a death. Massey is charged only with aiding and abetting to assist in a suicide.

The hearing before Judge Wilton was scheduled to take place at 1 p.m. on December 8 at the Dakota County courthouse, 1560 Highway 55, Hastings, Minnesota. It was open to the public.

NOTE: Final Exit Network members will receive an e-blast as soon as any final judgments are announced.

Our Newest Board Member

Dr. Martin Seidenfeld serves on the Board of Directors of the Final Exit Network. He has been a clinical psychologist for over 30 years with an independent practice in New York and Boise, Idaho, where he currently lives and practices. Dr. Seidenfeld has been an associate professor at Boise State University, at The College of Idaho, SUNY/

Farmingdale and elsewhere. He is a former President of the Idaho Psychological Association and was founder of the Idaho Hotline for Suicide Prevention and of a residential treatment facility for troubled teens.

For many years Dr. Seidenfeld provided counseling and psychotherapy for distressed individuals, including having a popular radio



Dr. Martin Seidenfeld organized and spearheaded the recent, successful AARP demonstration in San Diego.

call-in program. He has presented workshops and seminars in all 50 states as well as overseas. His goal in all of his activities has been to help reduce human suffering.

[Marty's first major project as a board member was to mastermind the San Diego AARP protest, and did he hit the ground running! Ed.]



Today's "Kooky" = Tomorrow's "Brilliant"!

What a good idea Wye Hale-Rowe had for AARP to develop something–pill or mechanical device or spray, whatever–that will make death as dignified and even joyous as AARP perceives our aging lives. I'm sure their membership would increase. Of course, they'd sell it–and we'd gladly buy it.

Dying peacefully does not require rocket science. Where legislation has made it legal, the method is by ingestion or injection of certain barbiturates. The latter is available to our pets and to our friends in the Benelux countries of the Netherlands, Belgium, and Luxembourg. The former is accessible to people in Oregon, Washington and Vermont and Switzerland. It is simple but not accessible to you and me, or even to death row inmates.

Derek Humphry and I chaired the NuTech session on Saturday, 9/20/14 at the World Right to Die Conference in Chicago. The ERGO *Listserv* goes out to chemists, pharmacists, anesthesiologists, engineers, and to many others who might envision some new, creative, peaceful, quick and certain method–like a pill or a device, currently beyond our collective imagination, that would do what Wye proposes: lead us into a gentle death.

One of the principles of brainstorming is that people are free to voice ideas that may sound wild or kooky to others, even to themselves. Humankind is rife with ideas that sounded bizarre when they were first expressed, but that later grew wings and soared. (Didn't history's most dramatic and productive innovations first find expression through the mouth of **one person** who had the courage to voice them, even if it felt foolish to do so?)

Derek and I want to hear your kookiest, most outrageous ideas, as well as others that sound

more "normal." Let us know how to contact you.

With thanks from all humanity.

- Faye Girsh (fayegirsh@msn.com) or Derek Humphry (ergo@finalexit.org), put NUTECH in the subject line.

* * *

May, 2014, two elderly, well-respected and very ill brothers shot themselves at home in Edinburgh. Armed police roadblocked the area, and a police helicopter swooped overhead. There was no doubt about the seriousness of the brothers' conditions, no doubt that they were mentally competent, no doubt that the incident was entirely free of foul play. The doubt targets a supposedly civilized society that cannot organize a better backup, better legal choices, a better expression of humanity, for those most in need at the end of their lives.

Two good people were forced to die alone, in secret, by doing violence to themselves, while politicians and preachers play and pray, while they utter sound bytes and claim (through some secret channel unavailable to the rest of us) that God is on their side. All I can say is God help us, for his emissaries clearly won't.

-Chris Docker (Director, EXIT, 17 Hart Street, Edinburgh UK) from Listserv 6/3/14

* * *

Re: A Study of Outcomes in Oregon

Compared with other family members of decedent Oregonians who did or did not request aid in dying, there appeared to be little impact on mental health outcomes, including prolonged grief symptoms and diagnosis, depressive symptoms or diagnosis, or mental health care use. However, as compared with control families,

FYI continued on page 26



families in which aid in dying was requested were, on average, more prepared for the death, more accepting of the loved one's death, and less likely to endorse that they wanted more.

It is important to note that the author, Dr. Linda Ganzini, is not stating that the hastened death per se caused more acceptance but rather that the process itself-requiring in most cases that the individuals have detailed conversations with their loved ones-may well have been the most vital piece in ensuring this better outcome. I do think it is helpful evidence in refuting the claim that such suicides cause depression and grief in family members, a false claim I recently saw posted on the web. – Janis Landis

More Kudos for the Previous Exit Guide Training Program

Thanks for your acknowledgment, Dick Mac-Donald, but your enormous contribution needs to be noted too. You have been the backbone of

* * *



our training programs over the years. Your contribution this year, as always, was invaluable

Bob Blake also deserves thanks for his many insightful comments and his ease and willingness to participate in role-playing.

New blood is always

needed in a small organiza-

Dr. Tom Tuxill

tion like ours. The Training Committee was energized by the number of new people willing to serve and further our mission. Wendell delivered a great pep talk at the conclusion of the training session that raised electricity in the room.

Thank you all, for an exciting and productive team experience. - Tom Tuxill, M.D.

* * *

We frequently get asked questions about Death with Dignity or advance-care planning for situations where dementia might be involved.

Many individuals have concerns about confronting Alzheimer's disease or other dementias in the future; others are in the midst of difficult and frightening situations when their family members are struggling with the disease.

The uncomfortable reality is there are no easy or clear cut answers. None of the three states with Death with Dignity laws allows individuals to participate who have dementia or Alzheimer's disease which has advanced to the degree where judgment or decision-making is impaired. But there's a Catch-22: Those with early stage dementia without cognitive impairment do not qualify because they do not have a terminal diagnosis. - Peg Sandeen, Ph.D. Exec. Dir. Death with Dignity, from a report 7/3/14, via Listserv

* * *



Linda Banez and Wendell Stephenson staffed the Final Exit Network booth at the Unitarian Universalist General Assembly in Boston in June.

I returned from the Unitarian Universalist General Assembly on Monday, June 30. Linda Banez and I were at the booth from the start on Wednesday, June 25. We were joined by Judith Hinds, a member and a new Associate Guide out of Vermont Thursday through Saturday, and by Stephen Kuhn, a member from MA, on Friday. The assembly finished on Sunday, June 29.

All of us who staffed the booth thought it was very worthwhile for FEN to be represented there. We talked with hundreds of people, almost all of FYI continued on page 28

Final Exit Network 2014 Financial Report

Money Matters

Reminder for members: Please designate on your checks whether they are for membership, renewal, or donation. And remember that all are tax-deductible!

The past fiscal year, July 1, 2013–June 30, 2014 was good to us financially as our income exceeded our expenses by \$39,460. Our largest income came from donations followed by



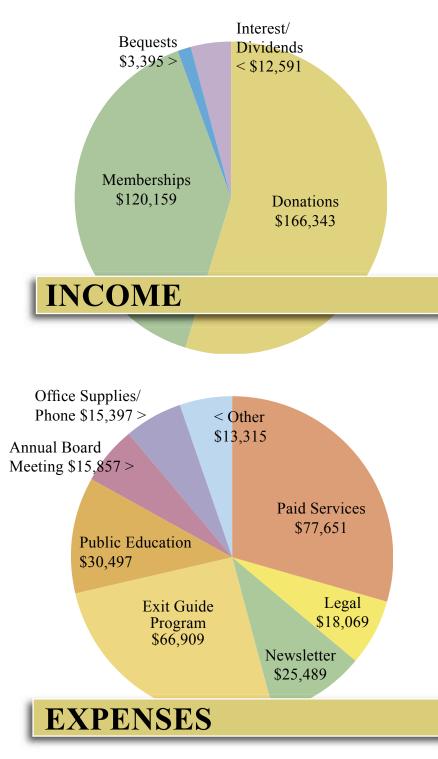
memberships. Bequests, though, were way down, and we will be working to increase those. Our largest expense was Paid Services, including Office Manager, Operations Manager, Bookkeeper, Database Manager, and Accountant, all

Judy Snyderman

contractors who work for us part time. Everyone else is a volunteer.

Our second largest expense was the Exit Guide Program, followed by Public Education. Still too many people do not know of our existence and suffer unnecessarily. We need to increase our membership and to do the marketing that will spread our name and mission. We expect that the wind beneath FEN's wings will be blowing vigorously this year!

- Judy Snyderman, Treasurer



RENEWAL CALLERS NEEDED!

We enlist volunteers who call members who have let their membership renewals slip. (A huge thank-you to June Roth, Alanna Gertz, Juanita Ainsley, and Marsha Malone!) But they and FEN would benefit enormously with more help, reaching our tardy renewers more quickly. The only requirement is a telephone with unlimited calling. If you are interested in helping, please email me at mmjudy4@gmail.com or call 866-654-9156 and let the answering service know you are interested in volunteering for the renewalcaller program. You will be asked to make about 25 calls/month.

The calls are usually pleasant; most members just forgot. You will have the satisfaction of performing a very important service. And you'll talk to some nice people. -Judy Snyderman



whom were supporters of the right to die and of us in particular, once they learned about us.

But at least half of the people who visited the booth either had no idea who we were or thought we were C&C or even the Hemlock Society. We encouraged people to join, donate, tell their friends, invite us to give talks, and sold a few of Derek Humphry's books.

There is no statistical way to determine our impact. But if the people who would naturally be supporting us don't even know we exist, we need to be there in force each year. The assembly will be in Portland, Oregon next year, and we can reasonably get 6-8 volunteers to be at the booth during the assembly. That's far preferable to the 3-4 that we had, as Linda and I were quite tired by the end.

Luckily, I was empowered each night by some very high quality, locally-brewed beer.

* * *

– Wendell Stephenson

We Get Mail: Nays and Praise

The "new look" newsletter is terrific! Bouquets of roses to all whose research and creativity went into its production. [*Those are Julia Hanway's doings. Ed.*] Lee, it was brilliant of you to find and include the pieces by Bill Maher and Scott Adams.

- Ruth von Fuchs

I am appalled that Final Exit Newsletter published a stale, sleazy gibe at women in its February 2014 issue. Bill Maher writes that a British man brought his wife along when he sought assisted dying in Switzerland "because nothing gives you the nerve to go through with it like having the old ball and chain yapping away."

Death with dignity is a matter for somber, principled people, not an excuse for smarmy sexism.

-M.S. (RTD supporter since the '80's)

It occurs to me that non-members who happen upon the last NL (Winter, 2/14) may feel sufficiently repelled by Bill's article that they would not consider joining Final Exit Network, which would be a great pity. – *Muriel Sterne*

[Those of you who are familiar with Bill Maher know that he often crosses lines. I used his article because I was delighted to see his support of us; not too many celebs have been

eager to do that, to my knowledge. And because I know how deeply involved he has been in the rights of all who are picked on by society-atheists, gays, minorities, and women-I was able to see that line and enjoy its utter outrageousness. Had it come from specific, other people, I would have seethed.



Lee Vizer writing in r

That said, I appreciate your writing in response to the article. Ed.]

* * *

More Perspectives

In my almost 20 years as a hospice RN. I have seen too much suffering. So many patients asked, begged for a peaceful way to die. Instead, we loaded them full of medication and allowed their dying to drag out, taking with it the one thing people prize most: dignity.

When I spoke at the World Federation of Right-to-Die Societies in Boston (2000), I had hoped that by now, 14 years later, we would have seen some dramatic change. There has been some. A couple more states were added to the RTD corner. A handful out of 50.

The suffering that people endure: pain, respiratory distress, anguish, anxiety, insomnia, intractable nausea and vomiting ... the list goes on. Day after day of endless and hopeless misery.

Although hospice has done great things with our multidisciplinary medical, psycho-social and spiritual approach, we still are unable to promote a basic concept: self determination. We support our patients, walking with them through the dying process, easing their suffering in almost any way we can. But we stop short when the patient

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Once you hit "Post" you can go back to your posting and find the drop down menu under the check mark to the right of your posting which will let you revise or delete it, so your initial post is not carved in stone.

asks for aid in dying. We change the subject, tell them we can't, or just add more meds.

Time for change is past due. While the issue is discussed to death, patients endure unspeakable torture.

Maybe we need another champion, another Jack Kevorkian. Who knows? At that time it was a medical doctor who was able to spark discussion of the right to die. Perhaps this time it will be someone else... maybe even a hospice nurse.

– Douglas Aberg, RN via Listserv

* * *

Lucky Us!

Those of us involved in the DWD movement, especially working volunteers in FEN, are exceptionally blessed. Whether our role is simply to send in our dues and explain our organization to interested others, or to be carrying picket signs in San Diego, or to serve as a case coordinator, board member, exit guide or affiliate leader, we have a cause that really matters, and we have found it late in life, when we are not likely to start a second career or a second family. Many people past retirement age feel lost as grown children leave the nest and careers have been completed, but we continue to have a purpose that gives real meaning, relevance, complexity and challenge to our lives. How satisfying it is that our cause serves a neglected and deserving population: the sick, the suffering, and the elderly. While our youthcrazed society focuses on the trendy, the young, and the hip, we instead have the purpose of bringing peace of mind through information to

those unnerved by age and illness, to give them choices and to accompany them by phone or in person through this difficult terrain.

Whenever my own life ends, I will always be grateful for having spent my last decades in this quiet but important work of Final Exit



Ann Mandelstamm

Network. And my heart bursts with gratitude for all those colleagues in the Network–witty, wise, emotionally generous, and dazzlingly courageous–with whom it has been my great privilege and inspiration to work and serve at their side.

– Ann Mandelstamm

* * *

In Chicago, Fran Schindler asked me to add the number of calls and web contacts FEN coordinators make to Tom Tuxill's excellent report at the FEN annual board and advisory board meeting. Since 2012 we started collecting those figures and attaching them month-by-month to our count. The figures are cumulative.

- In 2012, there were 751 calls to the 1-800 line for 9 months of data, and 351 web contacts for 7 months of data.
- In 2013, there were 1062 calls to the 1-800 line for 12 months of data, and 573 web contacts for 12 months of data.
- In 2014 (8 months so far) there have been 710 calls to the 1-800 line and 301 web contacts.

Coordinators Fran Schindler, Beverly Kobrin, Ann Mandelstamm, and Joan Sophie do an amazing job! They are the face of the Network's most consistent interaction with the public, and each of them is the perfect person to handle that contact with both compassion and knowledge. Their contribution is immeasurable.

– Dawn Pollock

FYI continued on page 30



Dementia or Dignity?

Gillian Bennett dragged a foam mattress from her home on Bowen Island to one of her favorite spots on the grass, facing a craggy rock cliff, the place she had chosen to die.

Bennett, 85 and in the early stages of dementia, chose to take her own life with a draught of good whiskey, a dose of Nembutal mixed with water, and her husband of 60 years by her side. "I held her hand," said Jonathan, a retired philosophy professor, and in a reflective and resonant voice, he added," I agree with her choice."

Before the shadows of dementia began to cloak her mind, Bennett had created a website, deadatnoon.com, to be revealed after her death, on which she made a passionate plea for physician-assisted options for the seriously ill and elderly.

She was painfully aware of the encroaching dementia: "I am becoming a vegetable," she wrote. "Every day I lose bits of myself, and it's obvious that I am heading toward the inevitable state of not knowing who I am and requiring full-time care."

Bennett wanted to face death as she had faced the challenges of her life: with intellectual curiosity, courage and grace. She did not want to be a carcass, "physically alive but with no one inside." So she decided to end her life before her mind was totally gone.

"She wouldn't let me help her, and I didn't wish to," said Jonathan. "I don't know where she got the Nembutal or the instructions; she didn't tell me." Nor did she let him help her drag the mattress outside, although that final effort was physically

difficult for her. One thing her husband did know for sure: "She was absolutely not frightened. Not even slightly. Calm and peaceful."

After she passed away, Jonathan let go of her hand and called her doctor, who came, confirmed death and notified the police. An officer interviewed Jonathan, and together they awaited the coroner. "The policeman asked me what happened and I told him. He was very efficient and civilized and good," said Jonathan. The officer's respectful treatment was a small comfort. Jonathan knew that if anyone had assisted her, they would be breaking the law.

"Gillian and I both disliked and disapproved of laws that made it impossible to help a loved one with something as important as death." His brilliant, beautiful wife, who once had a thriving clinical psychotherapy practice, had made the choice which she felt was morally and ethically correct.

Dementia had crept in bit by bit. Lately, Bennett became increasingly forgetful, hyperfocused on certain things, obsessing non-stop about others. "She was failing more quickly in the last six months," said her daughter Sara, "and she knew it."

During lucid moments in the last two years, Bennett wrote about her decision: "Vegetating for years in a hospital, in diapers, incompetent, a financial and physical burden" was unthinkable, ludicrous and wasteful.

It wasn't only the thought of burdening others; she was also considering the kind of life she would have: hard on those who loved her and not at all good enough for her. Visit her website: www.deadatnoon.com

By Denise Ryan, Vancouver Sun, 21 August, 2014 via Listserv

You might be interested to learn that the husband of the woman described above (from Derek's *Listserv*), Jonathan Bennett, is a wellknown (by colleagues, at least) philosopher who has written numerous influential, well-received

> books and articles in philosophy. One of his best, which I use every term in my Ethics course, is called "The Conscience of Huckleberry Finn."

I note that he says he "agreed with [his wife's] choice," and that he was there with her when she ended her life.

Many professionals in the field of philosophy are supporters of death with dignity. Makes sense to me!

– Wendell Stephenson

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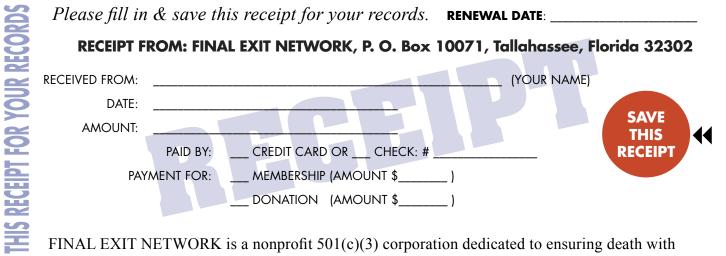
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