

**Notes from the
World Federation of Right to Die Societies
17th World Congress Biennial Conference - June 2012
Zurich, Switzerland**

by Faye Girsh

Day 1

I got here yesterday in the cold rain. Staying at the Swissotel, a big, modern building near the train station. Cold as it was it was warming to start bumping into old friends from Europe, Canada and Australia. This is an expensive city! Ted Goodwin, the current WF Prez, and I went across the street and had plain spaghetti, nothing else, for \$10. The currency is colorful and beautiful but hard to hold on to.

Today about 15 of us had signed up for a tour led by the conference organizer, Bernhard Sutter, VP of **Exit Swiss Deutshe** here in Zurich. Besides being young, energetic and delightful he has put together an amazingly wide array of speakers demonstrating just how broad the World Federation is. Tomorrow I'll report on the actual program so you'll see what I mean. This morning he led us – on trains and trams – to the charming, rustic, vibrant old town, which unfortunately is pretty far from our hotel. Among other things we saw a church with Chagall windows. The weather was good, thank the Swiss gods. Around noon we went to a river boat where we sat down to an elegant lunch while cruising down the river. Both banks were right out of a post card with their pretty homes, picturesque steeples, and lots of green. It did rain a few drops while we wined and dined but was OK for some of us who returned by tram to the hotel. Most of the others climbed one of the hills and were drenched by the heavy rain that continued sporadically thru the evening.

At 4 the old board, plus Neil Francis – soon to become the next WF Prez – met for two hours discussing some of the proposals the Delegates would vote on tomorrow. One of them is mine which is to consider having Individual Members. Now all “members” are RTD societies. Another agenda item for the Delegates is the election of the board which we try to keep as geographically diverse as possible. I am staying on as Newsletter Editor and possibly VP again, unless there are nominations from the floor. Immediately following our deliberations was the welcoming party where old and new friends meet, drink, chat, and munch. I always find it amazing to see friends from Israel, Japan, Sweden, New Zealand, Australia, Canada, Scotland, Luxembourg, the Netherlands, Belgium, England, Monaco, Switzerland, Zimbabwe, Germany, and more. Bernhard said there would be 40 countries represented – all with the idea of providing choice and dignity at the end of life.

More serious discussion followed thanks to a brain storming session with a dozen of us, called by Neil. I don't remember a meeting like this before where we exchanged ideas about how the WF could be more helpful to our members and their members. No conclusions were reached but it was productive and lively. I did learn at least one thing today which surprised me: that fast acting barbiturates used for assisted dying and voluntary euthanasia are not available in the

countries where they are used. Now they have to be gotten from places like China and Africa. I will look into this more but apparently some of the opposition we see in the U.S. is also at work in the countries we think of as most progressive.

More tomorrow when the conference opens officially.

Day 2

Besides the sun coming out, a lot happened today at the World Federation meeting. Ted Goodwin opened the proceedings by reviewing accomplishments in the RTD world in the last 18 months since the last meeting in Melbourne – and there were a lot. Because there is a rift in the WF between those organizations that want to stay within the law and the others, and between **RtD-Europe** and the WF in terms of supporting the efforts of Europe to the exclusion of the worldwide efforts, Ted chastised those who would erode the unity of our efforts by inserting division in the ranks. He mentioned the people he admired for their courage including Michael Irwin and Jack Kevorkian and did not mention that he has twice been indicted for his activities with the **Final Exit Network**.

Nominations for the Board were presented and voted on. The new officers are: Neil Francis for President. Neil is CEO of **Dying with Dignity Victoria** and also of the Australian umbrella organization, **Your Last Right**, which was launched in Melbourne at the 2010 WF meeting. I continue to be Vice President and Newsletter Editor, Ron Plummer (from Monaco) is Treasurer, and Berit Hasselmark, an enthusiastic retired nurse from Norway is Secretary. At large directors are: Dr. Rodney Syme (also from Down Under), Dr. Iwao Soichiro, President of the **Japan Society**, and in a later nomination from the floor, Jean-Jacques Bise, board member of **Exit Suisse Romande**. It should be fun working with this new board representing six different countries.

Michael Irwin gave the Treasurer's Report which seemed good though there is some contentiousness about some European societies not paying their 1% of dues and preferring instead to contribute to **RtD-Europe**. To solve a problem that had long been bothering me, I had introduced a motion for Individual Memberships, an idea that goes against the idea of a Federation of Societies. There were lots of suggestions during the discussion about how we could improve membership but the truth is we have 46 members – all RTD organizations and some with very small memberships. Individuals cannot join, though they can subscribe to the Newsletter. Bottom line was that the Board is instructed to come up with a plan to incorporate individuals into the organization in some way – by December.

It was exciting to induct four new societies into membership. They are: **SOARS (Society for Old Age Rational Suicide)**. Founder Michael Irwin discussed polling data indicating strong support for this concept. **The Farewell Foundation**, based in Vancouver BC by Russel Ogden is involved in an important court decision in Canada which will be decided momentarily. The object is to assist with self-chosen death using an open model where deaths would be immediately reported. **Life Circle** in Basel, Switzerland, is the third group founded by Dr. Erica Preisig who was with **Dignitas** and now wants to create a similar organization that will also

accept foreigners. France contributed the fourth organization, **Ultima Liberte** which is impatient with the progress made by the existing French society and wants to experiment with the idea of obtaining our freedom without doctors. They were welcomed into the ranks.

Rob Jonquiere, the WF Communications Director, explained the intricacies of the WF website (www.worldrtd.net) which lists contacts points for all member organizations, newsletters from around the world and from the WF, news, scientific information, book reviews, and much more PLUS Rob is having the news translated into German, French, Italian and Spanish! Quite an information source and an impressive accomplishment. You can go to the web site and sign up for a monthly update.

After a delightful buffet lunch we reassembled to hear four programs.

The first was by a Japanese man, Yukio Matsuo, whose wife was in a head-on collision and has been unable to communicate except through her eyelids. She has expressed her love for him but also her wish to die. He published these in three small books – *A Message from Makiko's Soul*. In Japan there is still no law permitting refusal of treatment. He quoted the words on Mme Butterfly's sword, "He shall die with honor who no longer can live with honor".

Dr. Aycke Smook, President of **RtD-Europe** spoke next on the history of that organization and the parallels with the WF. He mentioned that adequate medication is no longer available, even for doctors. Also that the best palliative care is talking about the end of life though there has been relatively little success in getting laws changed in most of Europe. He preferred using the term "fellow human beings" to "patients".

Richard N. Cote, author of the newly released book, *In Search of Gentle Death*, reviewed developments in the Americas. He has special knowledge of Latin America since his wife is from Colombia. He mentioned that there is an ACLU suit in New Mexico challenging assisted dying laws and reminded us of the Colombia Constitutional Court decision in 1997 permitting assistance in dying and that this is going on, unregulated, in that country.

The fourth event was a panel, "*Three Pages in the End of Life Choice Book*". Dr. Rodney Syme indicated his dislike of medicalized dying though he did think the doctor should be the one consulted to determine if the person is appropriate, the medication should be given, but that the person should take it herself when she felt it was time. I spoke about the model of the **Final Exit Network** which is a non-medical model of necessity since medications are not available. But Exit Guides are not doctors (though they can be). Michael Irwin reviewed some models and stressed the diversity of the approaches now used.

Following a tea break Neil Francis presented us with some of the ways he uses the computer to store quotes from friends and enemies, facts in the RTD movement, and research on known adversaries. His ideas were well-received even for those of us too low-tech to think of them ourselves but glad to be led by someone with such a good mastery of technology (www.yourlastright.com). Later, at the **RtD-Europe** meeting Dr. Jan Bernheim demonstrated how palliative care works well with voluntary euthanasia in Belgium and how it has improved people's confidence in the health care system.

Dinner out of doors on this beautiful night with friends at Los Tres Amigos provided a well-deserved Swiss/Mexican finish to a long, interesting day.

Day 3

Another nice day though I didn't actually experience it till 7 p.m. when I went to dinner with Larry Egbert and his wife Ellen. Today was *Public Day* which means that the members of **Exit Swiss** were invited at no charge. Other people had to pay ch130 which scared some folks away. There were some short meetings in German early (we had ear phones with translation into several languages but the ear pods hurt so it was grand to have English speakers, since most spoke in German). The first major attraction was Sir Terry Pratchett whom most of the world now knows because of his amazing You Tube recordings (e.g. *Shaking Hands with Death*). Wearing his characteristic big brimmed black hat and white beard and mustache Sir Terry explained that because of his condition of posterior cortical atrophy he can't read but had a young man read his speech (he can still write and think clearly). He had been active in establishing the *Falconer Commission* in GB to make recommendations about assisted dying. He expressed his disappointment that the recommendations are being ignored. Meanwhile, he pointed out, Brits go to **Dignitas** to the embarrassment and shame of Great Britain.

There were speakers and panels all day so it would take pages to describe all of them (and much of the program will be on the WF website). I will take the liberty of telling you about what I thought were the highlights. One was Ludwig Minelli's startling talk, *Suicide Prevention and Suicide Attempt Prevention*. (I hope I get this right since Mr. Minelli has chastised me before for misquoting him.) In 1997 Swiss government reported that for every successful suicide there were between 10 and 50 failed attempts. In a country of 8 million that would be 67,000 failures at an estimated annual cost to the country of 2.4 billion Swiss francs (about equivalent to US dollars). Minelli attributes some of this tragedy to society's negative value of suicide making it almost impossible for a person to discuss a desire for suicide without condemnation or psychiatric commitment. In **Dignitas** a person can discuss his plans openly without patronizing or taboo. This approach would allow many desperate individuals to continue living. (This excellent paper is available at <http://www.dignitas.ch> since I cannot do it justice in this space).

Another talk which shook everyone up was, not surprisingly, by Philip Nitschke who advocates a non-legislative and non-medical approach where individuals can obtain the means to a peaceful death. He used the controversial Lisette Nigot case to demonstrate that even if you disagreed with the wishes of a healthy 80 year old woman to end her life she has the same right of self determination and does not want to be judged. She argued that death is not a medical process and that she just wanted the information to use herself. Nembutal is easily available these days, Nitschke argued, as are other means not involving doctors. Of course all the information is in his *Peaceful Pill Handbook* and having that would render the efforts at law reform void – a controversial position to say the least.

There were several discussions of palliative care pointing out that it is valuable, not available enough in Switzerland, not working well with assisted dying, and often rejected by patients who

have had enough. Dr. Jan Berrnheim spoke about the excellent cooperation between the two in Belgium and how it could work here if there weren't competition and mutually negative attitudes. Several case reports were presented where loved ones reported peaceful deaths at one of the four (soon to be five) facilities in Switzerland. There was agreement that not all is perfect here and, that even with a peaceful death, suffering can occur. There is soon to be a referendum in the *Canton of Vaud* on the use of assisted dying in nursing homes and senior facilities. Dr. Roger Kusch talked about his new program for assisted dying in Germany and Dr. Chris Arnold told me that the court decided favorably in a case where he provided assistance and the medical society objected. Florida attorney George Felos explained the convoluted intricacies of the Terri Schiavo case and its implications for religion, politics, and family divisions to make a mockery of settled law. Panels reviewed the situation around the globe and one religious person gave a heavily cliched talk about what is really needed at the end of life. Two wise sentences stuck out for me: It is doctors who are afraid of death more than anyone else. And, it is important to see suicide as a social and individual phenomenon if we are to prevent it (Minelli).

A beautiful buffet lunch was served to the several hundred people present. I have to admit to feeling privileged to be rubbing elbows with Minelli, Pratchett, Nitshke, and most of the major players in our movement (Derek Humphry was unable to attend and many sent their regards). People not involved in these bi-annual WF conferences miss the opportunity to hear challenging new ideas and meet the pioneers in our movement. It is to the great credit of Bernhard Sutter, the organizer of this meeting, that divergent and unpopular views were heard as well as opinions from religious folks. By the way, the opposition was supposed to be holding a conference across the street, upstairs of McDonald's. Billed as 700 people apparently 10 showed up to pray; no disruption occurred.

Tomorrow: a visit to **Dignitas**, the *NuTech* meeting, and the Banquet. Stay tuned.

Day 4

If this wasn't the longest it was certainly the best day of the conference with the victory from British Columbia! I found out at the WF Board meeting at 7 a.m. this morning. At 9 the bus came and took about 30 of us to **Dignitas House**, the unusual, cheerful, brave little spot where Minelli set up the house for people being accompanied to die. It is about a 20 minute drive from Zurich past rivers, fields, snow-covered mountains, pretty Alpine homes to a sudden stretch of vegetable fields on one side, industrial buildings on the other, and sandwiched in between a small complex of blue, low buildings which comprise a little restaurant, where a cheerful Croatian woman serves meals to the industrial workers, a small dining area, a lovely garden with a little waterfall and goldfish and lots of green plantings, to a small, light, cheerful, open house with three bedrooms and places to sit and tables to write at, and bowls full of Swiss chocolates where people go, with their family, friends and/or Dignitas accompanier for their last drink. We could not help being in a good mood. There were notices of the Canadian decision put out, plates and plates of delicious food, and Ludwig Minelli himself pouring wine and feeding the fish. I cannot remember a better day in the RTD movement what with being at this pioneering place of rest and celebrating a significant legal victory on this warm, sunny Swiss day with RTD supporters from all over the world. It was a wonderful experience.

After a few hours at this little house in front of a big factory we returned to the bus and were taken to the **Dignitas** offices. This was in a green, lovely, residential neighborhood a half, scenic, hour away where records are kept, phones are answered and the business of Dignitas goes on. The headquarters, now 4 years old, are light and spacious and look both efficient and friendly. I think we were told there were 15 part-time employees, some just in the office and others who work with the people who come to Dignitas. The staff was mostly young, friendly, helpful and hospitable.

From there we were back on the bus and returned to the Swissotel in time for the 2 p.m. **NuTech** meeting sponsored by **ERGO** which I chaired and organized. It was standing room only in a room that held about 50. Because we only had three hours and six speakers timing was tight. Dick Cote started by showing beautiful pictures of the history of NuTech with some of the founders like John Hofsess, Rob Neils and Derek Humphry. He also showed some of the early inventions like the debreather which eventually morphed into the helium method so popular today. (For a thorough history of NuTech read his informative book, *In Search of Gentle Death*.)

From there Dr. Boudeiwjn Chabot (The Netherlands) showed a beautiful DVD he has produced where a distinguished older man ponders the end of his life, decides on the helium method, makes an exit bag, and explains how to use the tank and bag. It takes place in a lovely house which, as it turns out, belongs to the Chabots. (I don't think I would be anxious to leave this world if I lived in that house!). He is selling that DVD for 20 dollars US. It was done in English, French or German. (We will have to report later about how you can obtain a copy).

In case helium was not a choice a variety of other methods were presented. Neal Nicol (long time colleague of Jack Kevorkian's) developed a prototype of a carotid artery compression device. Theoretically the blood supply to the brain would be quickly cut off and a painless, quick death would occur. This apparatus has not been tested. This is a variation of what Ruth Van Fuchs suggested many years ago at a NuTech meeting in a more primitive version, the *Killer Potato*, where compression was caused by two potato halves. More research is needed to determine if the brain stem remains viable after the cortex dies.

John Todd (Australia) developed a variant of Philip Nitschke's *COGenie*, a way of releasing carbon monoxide through the interaction of formic and sulphuric acids. This is a complex arrangement of bottles which when activated would expel CO through nasal tubes. John has reported success with this device though it seems like it would require assistance.

Tijn Hagens, who works with **DeEinder** in the Netherlands, recommends the use of helium or various drug combinations to those patients not eligible for help through the regular Netherlands legal channels. Apparently Nembutal is available on the internet or there are various other drug combinations that patients are told about including chloroquine and valium combinations.

The last speaker was Dr. Rodney Syme who is concerned that if Australia is successful in permitting physician aid in dying what drugs would be available since Nembutal and Seconal are not possible to obtain legally there. He pointed out the irony that veterinarians have access to liquid Nembutal for seven dollars a dose where it costs more than a thousand US dollars in

Oregon and is not available at all to docs down under. I think we knew that having a peaceful death does not have to be a high tech problem. If the law were changed cheap and effective Nembutal would do the job quickly and easily.

We still had time for a lively discussion before going to a delightful cocktail party at 5 and thence to a banquet celebrating **Exit Swiss's** 30th birthday where wine flowed, steak was eaten and desert was at a self-service bar. The last supper, as it were, is traditionally when awards are given by the WF. Tonight was no exception. The *Tenrei Ohta Award* is given by the **Japan Society** to the person who had the most influence on the global RTD movement. Human rights attorney and **Dignitas** founder, Ludwig Minelli, was the recipient. Like yesterday he stressed the importance of preventing unsuccessful suicide attempts and, in this way, protecting and saving life. "We are a pro-life organization" he said, to applause.

The *Marilyn Seguin Award*, named for a pioneering RTD worker in Canada and founder of **Dying with Dignity Canada** was presented by Marilyn's good friend and fellow Canadian to another pioneering Canadian, an academic researcher and now activist and founder of the **Farewell Foundation**, Russel Ogden. Till yesterday, Russel said, Canada had an absolute prohibition against assisting a death. Now that constitutional provision is invalid and a new law can be crafted giving the widest possible access to those who need it while protecting the vulnerable.

Dr. Michael Irwin presented the *Health Professionals Award* to Swiss oncologist and retired politician Dr. Franco Cavalli. Despite Switzerland's liberal position on providing assistance to the dying and its five highly effective organizations Dr. Cavalli is campaigning for expanding these rights to include voluntary euthanasia to those unable to help themselves. He sees the RTD not as a movement for dying but as a movement for life.

And so ends the 17th World Conference – an indescribably memorable experience. It is anticipated that the next conference will be in October 2014, in Orlando and hosted by the **Final Exit Network** and **ERGO**.

See you there! For the next two days some of us will be touring the rest of Switzerland, set up by **Exit Swiss**.

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Note: Faye Girsh's notes edited, formatted and published as PDF (and for the web) courtesy of ERGO. Please submit any corrections or additions to ergo@finalexit.org and cc to fayegirsh@msn.com.



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